CURRENT AND FUTURE DEVELOPMENT OF INTERMEDIATE CARE FACILITIES FOR THE MENTALLY RETARDED

A SURVEY OF STATE OFFICIALS

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by

Mary Ann Allard
Human Services Research Institute
Washington, D.C.

Gail E. Toff
Intergovernmental Health Policy Project
George Washington University
Washington, D.C.

Intergovernmental Health Policy Project
The George Washington University
1919 Pennsylvania Avenue, N.W.
Suite 505
Washington, D.C. 20006
(202) 872-1445

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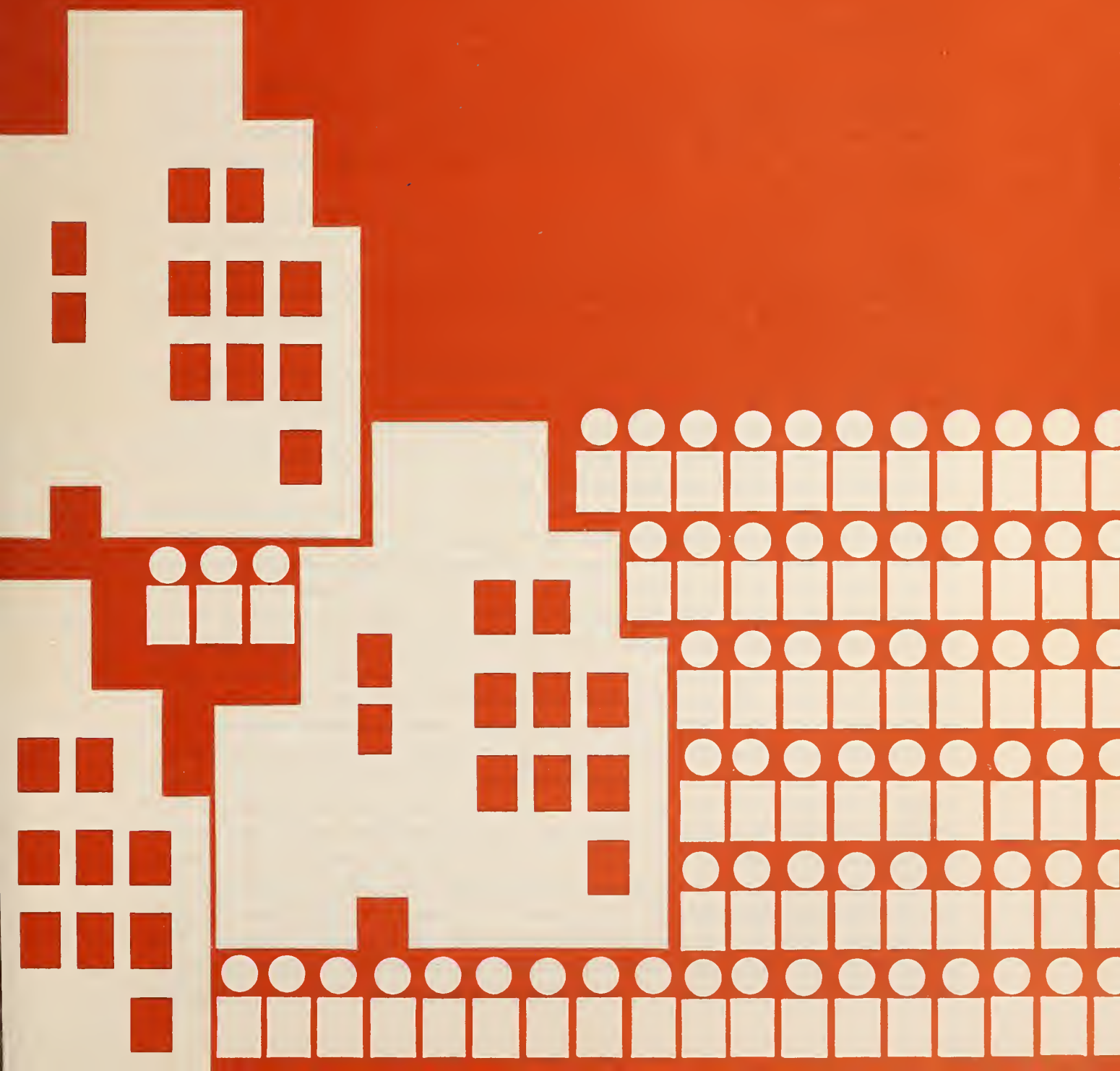
List of Tables

Table of Contents

I. BACKGROUND



A. A Brief Overview of the ICF/MR Program

1. Background

The Intermediate Care Facility Program for the Mentally Retarded (ICF/MR) was added to the Medicaid (Title XIX) program as part of the 1971 amendments (P.L. 92-223) to the Social Security Act. In that year, the ICF/MR program became another optional service that states could offer under their Medicaid program.

The initiation of the ICF/MR concept is important to review since there have been many interpretations of the legislative intent behind the program. Some believe this to be a strictly medical program, while others feel it should be a habilitative program due to the client population it serves. Still others are unclear how the program should be operationalized, i.e., are small ICF/MRs appropriate given the current federal standards?

Prior to the 1971 authorization of the ICF/MR program, federal Medicaid funds were available for states to provide care to disabled adults in private (non-profit and proprietary) facilities, but not for those persons residing in public institutions. Public institutions, however, also were eligible for Medicaid funding, if they qualified as skilled nursing facilities (SNFs).

As a result of these incentives, some states were converting their public institutions to highly medical facilities in the late 1960s (e.g. **California, Pennsylvania, Wisconsin**). Others, however, were moving eligible retarded residents from public facilities into private facilities — either nursing homes or proprietary board and care homes. During this same time, the General Accounting Office (GAO) completed a study examining the level and extent of reimbursements for retarded institutional residents, specifically focusing on hospitals operated by the State of California. The review concluded that Medicaid reimbursement to public institutions was illegal under existing federal law, and recommended that HEW recover payments from all states pursuing practices similar to those in **California.**

In response to the GAO recommendations, officials from several states sought a statutory change in Title XIX to authorize Medicaid payments for residents of publicly-operated institutions for the mentally retarded. In order to strengthen their position, these states, most notably **Oklahoma** and **Wisconsin,** sought the assistance of other organizations to help them develop legislative support for the plan. One of these organizations, the National Association of Retarded Citizens (NARC), was critical to the success of the legislative initiative. The price for their involvement, however, was a guarantee that facilities receiving Medicaid funds be designed to meet the habilitative goals of their residents and

provide active programming. In other words, NARC wanted to diminish the influence of the medical model which was predominant in Medicaid statutes up to that time.

The merging of the two primary interest groups (i.e., state mental retardation officials and consumer representatives) led to several major amendments that specified conditions necessary for certification as an ICF/MR provider. Some of these conditions are detailed below. At the time the 1971 Medicaid amendments were drafted, however, the focus of the debate was on large, publicly-operated institutions for the mentally retarded. As a result, the issue of how to fund small public and private community residences was not discussed in the Congress' statements of legislative intent when enacting the law. Moreover, although the 15-or-less concept was eventually worked into the regulations promulgated in 1974, even today there is no clear statement of federal policy concerning Medicaid reimbursement of small community-based ICF/MRs.

2. What is an ICF/MR?

An ICF/MR program must meet the following generic definition of an intermediate care facility. The institution or community facility must:

1. Be licensed under state law to provide, on a regular basis, health-related care and services to individuals who do not require the degree of care and treatment a hospital or skilled nursing home is designed to provide but who, because of their mental or physical condition require care and service (above the level of room and board) which can be made available to them only through institutional facilities;
2. Meet such standards prescribed by the Secretary for the proper provision of such care, and,
3. Meet such standards of safety and sanitation as are established under regulation by the Secretary..

P.L. 92-223 (Section 1905(a)) specifies that ICF/MR reimbursement is available for services provided in a public institution (or distinct parts thereof) only if:

1. The primary purpose of such institutions is to provide health or rehabilitative services for mentally retarded individuals and if the institution meets such standards as may be prescribed by the Secretary;
2. The mentally retarded individual is receiving active treatment; and,
3. The state or political subdivision responsible for the operations of such institutions has agreed that the non-federal expenditures with respect to services furnished patients in such institutions will not be reduced because of payments made under this title; (maintenance of effort provision).

When states exercise the ICF/MR option of Medicaid, however, they are required to cover not only mentally retarded persons, but also persons with "related

conditions." Related conditions were originally defined to include epilepsy, cerebral palsy, autism or other developmental disabilities as defined pursuant to Part C of the Developmental Disabilities Services and Facilities Construction Act. New amendments to this Act in 1978 and subsequent regulations further expanded the definition of developmental disability, changing its focus from categorical disabilities to more generic functional limitations. As a result, coverage now includes not only mental retardation, epilepsy, and cerebral palsy, but also chronic mental illness, spina bifida and any other physicial or mental condition which meets certain criteria specified in the amendments.

3. The Small ICF/MR (15 beds or less)

The January 17, 1974 regulations promulgating the ICF/MR program included the option that small facilities of 15 residents or fewer could qualify for Title XIX reimbursement. It should be noted that an "institution" as defined in Title XIX regulations means *"... an establishment which furnishes (a single or multiple facilities) food and shelter to four or more persons unrelated to the proprietor ..."* (45 C.F.R., Sec. 448.60(6)(1)). These small ICF/MR facilities may use the Life Safety Code standards for Lodging and Rooming House residences instead of the code for institutions. As a result of this new change, states were able to fund smaller, less institutional settings for the mentally retarded. These standards can be used under the following circumstances:[1]

1. For physical plant standards, (program and staffing standards may not be waived);
2. If residents were ambulatory, which must be certified by a physician or psychologist;
3. If residents are engaged in active treatment;
4. If residents are capable of following directions and taking appropriate action for self-preservation under emergency conditions; and,
5. If it will not adversely affect the health and safety of the residents.

At the time these statutory changes were made many states were already committed to a deinstitutionalization policy and believed that the ICF/MR option for small facilities would help them fulfill their deinstitutionalization goals. The 1974 regulations, however, provided very little guidance to the states pertaining to the conditions under which a small community residence could be certified as an ICF/MR provider. In fact, except for a few minor modifications in the 1977 regulations applicable to small ICF/MR facilities, and interpretive guidelines issued by HCFA in 1977 which provided some direction for states desiring to

[1] It should be noted that many states have placed mobile, non-ambulatory residents into small ICF/MRs using the Lodging or Rooming House Section of the Life Safety Code. A letter regarding the authorization of such placements was sent to Robert L. Okin, M.D., Massachusetts Department of Mental Health, from Hale Champion, DHEW, Washington, D.C. in March 1978.

develop small ICF/MRs,[2] DHHS has not addressed the question of certification of small community residences since 1974. As a result, states have had to utilize standards which were designed around the model of a large institutional facility and, as noted by many state officials, simply do not work when applied to the small 15 bed or less residence. Attempting to provide a small, family-like living environment in the context of the broad ICF/MR program has been a barrier for many states desiring to initiate small ICF/MRs. Furthermore, the vagueness of the regulations often slows many states' efforts to utilize Title XIX to encourage deinstitutionalization.

Although there have been attempts to establish and clarify HEW's policy regarding the use of Title XIX, ICF/MR program for small residences, there is still no overall federal policy guiding this program. Those states that ventured forth in the mid-1970s to develop community programs using the ICF/MR program, developed an ad-hoc approach to licensure and certification of small residential arrangements under ICF/MR. Although the program does permit the development of small residences that are not medically oriented but still "health related," the program itself is housed within a strictly medical program and must incorporate certain review procedures that are usually dominated by physicians and nurses.

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[2] Health Care Financing Administration, *Interpretive Guidelines for the Application of the 1977 Standards for Institutions for the Mentally Retarded or Persons with Related Conditions.* (45 C.F.R. 249.13) 1977.

B. The Reason for the Study

The ICF/MR program for both institutional and community settings is becoming an important and critical force in shaping residential environments for mentally retarded and other developmentally disabled persons. In Fiscal Year 1978, an estimated $1.5 billion was spent in ICF/MRs (both federal and state funds) to support disabled residents. For the most part, these funds have been spent in large institutional settings, with less than 20 states using the ICF/MR funding stream for community settings.

Although the Health Care Financing Administration (HCFA) which is in charge of the Medicaid program, does collect some information describing ICF/MRs, this data is usually one or two years out-of-date and generally is limited in scope. Some studies have been conducted by various organizations describing certain aspects of the ICF/MR program.[3] For the most part, however, there has been very little information available at either the state or federal level regarding the nature and potential impact of ICF/MR funding. In addition, very little information has been available regarding the ways in which states use, and intend to use, this source of funds in the future. Federal policymakers have also had little data available to them describing the major constraints that limit the responsiveness of the program, and the many program variations among the states that have pursued the small ICF/MR concept.

Several agencies recently have expressed an interest in gathering more detailed information regarding the ICF/MR program, including the increasing need to assess the current and potential characteristics of facilities and residents in the program. As a result of this interest, the President's Committee on Mental Retardation (PCMR) awarded a contract to HSRI to develop an initial study which would be used to capture current information on the ICF/MR program. During the course of the project, HSRI joined forces with the George Washington University, Intergovernmental Health Policy Project (IHPP) which had been ask-

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[3] See, for example, Center for the Development of Community Alternative Service Systems, *Intermediate Care Facilities for the Mentally Retarded (ICF/MR): An Overview of the Intent, Development, Provisions for Services and Current Usage of Medicaid Funds in ICF/MR Settings,* 1978; Federal Program Information and Assistance Project, *Intermediate Care Facilities for the Mentally Retarded,* 1978; Thomas Gilhool, *Working Paper on the Uses of Title XIX Sustain Community Residential Services for Developmentally Disabled People,* (First Draft), June 10, 1979; National Association of State Mental Retardation Program Directors.

ed by HCFA to look into similar programmatic issues affecting the ICF/MR system. Through this collaboration, the scope of the two individual projects was broadened, making it possible to produce a more comprehensive report.

In addition to collecting statistical information, such as the number of facilities, beds and clients in both institutional and community settings, this study designed questions to gain insight into the following: how states have interpreted certain program components of the program; how they have operationalized their small ICF/MR programs; and, the nature of the problems they face in implementing the program.

C. Project Methodology and Limitations

The purpose of the overall study was to collect information regarding:

- The current status of the ICF/MR networks in the 50 states;
- The scope of planned ICF/MR networks projected for the future;
- The key factors — economic, administrative, social and political — facilitating or inhibiting these networks; and,
- The federal policy and regulatory changes necessary to facilitate the development of such networks.

Given these general goals, HSRI and the IHPP employed a methodology similar to that employed by the National Association of State Mental Retardation Program Directors (NASMRPD) in their numerous reports to PCMR. As in those efforts, this study relied on structured telephone interviews with state mental retardation/developmental disabilities officials and other knowledgeable state officials to retrieve the necessary information.

The methodology consisted of eight major tasks:

1. Designing interview schedules to obtain estimates for the fiscal year 1978-79 and projections for 1983-84; data was requested for both state/county and privately administered facilities, for both ICF/MRs less than and more than 16 beds, for facility and client characteristics, and for the relative share of cost among the local governing unit, the state, and the federal government (a copy of the survey instrument can be found in the Appendix);
2. Contacting state mental retardation program directors by mail, informing them of the purposes of the study and requesting them to supply names of persons with knowledge of the ICF/MR program;
3. Arranging and preparing telephone interviews;

4. Conducting extensive phone interviews with one or more officials in respondent states;
5. Making follow-up contacts, where required, to secure missing information;
6. Supplementing interview data, where appropriate, with document reviews pertinent to particular state plans;
7. Reviewing general policy materials relating to the ICF/MR program;
8. Synthesizing the results of the interviews in a 20-30 page report.

A total of 42 states responded to the initial request for information, and telephone interviews were conducted in 39 states. Based on the number of states currently providing ICF/MR services (44), the response rate was approximately 89 percent. Though the response rate was high, results of the telephone survey should be interpreted cautiously. Much of the data presented is based on "best guess" estimates and approximations by state officials. Specific costs, especially the projected costs for 1983-84, were difficult to ascertain and should also be treated as tentative and somewhat speculative. For instance, some states only plan on a two year basis and could give estimates for 1984 that were, at best, educated speculation. Further, because the level of development of ICF/MRs varies so greatly from state to state, it is difficult to generalize about the program. For instance, "average" reimbursement rates for ICF/MRs within a state may represent only one or two facilities.

It should also be noted that the bulk of information collected during the survey was derived from state mental retardation/developmental disabilities officials. Although staff responsible for Medicaid certification and facility licensing were interviewed in some states, the major data source was state MR/DD officials. Thus, as a general matter, the data presented herein are only as good as the information available to such individuals at the state level. In the future, a more comprehensive survey should be implemented which includes respondents from the health and Medicaid agencies in each state.

D. Organization of the Report

The remainder of the report is divided into two major sections: Descriptive Analysis, and Issues for Future Development. In the first section, a summary of the survey data for both the existing ICF/MR system and future trends is presented. The summary includes statistical tables illustrating highlights in the data. State specific examples drawn from the open-ended questions are also included in the discussion where appropriate. The last section provides a more in-depth examination of pertinent issues emanating from the survey questions and results. The areas selected for closer scrutiny include:

- **Quality Assurance —** state licensing and certification procedures for small ICF/MRs; and the use of Independent Professional Reviews and Utilization Reviews; role of the state mental retardation office in licensing, certification, and policy coordination; and, the administrative auspices of ICF/MRs;
- **Planning —** current exemplary state programs; future plans for ICF/MRs-state specific; certificate of need process as it relates to ICF/MRs, and the relationship between institutional compliance plans and the development of community alternatives through ICF/MR;
- **Program Obstacles —** start-up problems associated with small ICF/MRs, controversies regarding size and medical versus habilitative, problems entailed in meeting ANSI, 504 and Life Safety Code requirements in small ICF/MR facilities; and other issues relevant to standards for model, both large and small ICF/MR facilities;
- **Funding —** alternative financing for residential care of the mentally retarded; relative costs of the ICF/MR program and its relationship to other federal funding streams, and the nature of the reimbursement systems developed by the states — especially for small ICF/MR facilities;
- **Policy Coordination —** HCFA's role in assisting states to implement small ICF/MR programs, the ways in which federal policy affects state coordination, the potential impact of the new developmental disabilities definition on the ICF/MR program, and the effect of lawsuits and court decrees on the development of small ICF/MRs.

II. DESCRIPTIVE ANALYSIS OF THE ICF/MR PROGRAM

Since its inception in 1972, states have used the ICF/MR program to provide residential placements for mentally retarded persons and others with related conditions in both institutional and community settings. This section of the report will present information by type of ICF/MR: small privately-administered; small publicly-administered; large privately-administered; and large publicly-administered facilities. Within each type of ICF/MR, four principal components are described: 1) facility characteristics; 2) bed capacity; 3) client characteristics; and 4) costs.

This information is based on a survey of 39 state respondents (See Appendix I for a complete list of the data elements and definitions of each type of facility). State officials were asked to provide ICF/MR facility and client data, "current" as of June 30, 1979, and projected to June 30, 1984. "Current" cost information was requested for the fiscal year July 1978 -June 1979. "Projected" cost information was requested for the period July 1983 - June 1984.[1]

Survey respondents were asked to provide the total yearly operating budgets (excluding capital improvements or repair costs amounting to more than $25,000) for each ICF/MR category. Providing total operational costs, and federal, state and local shares, however, was difficult for many of the survey respondents. The most complete information was secured on publicly operated large ICF/MRs.

If survey respondents could not provide the total costs, the average per diem provided by the respondents was multiplied by the number of certified beds in that category in that state, and then multiplied again by 365 (days) to develop a rough approximation of annual operating expenditures. (This figure was based upon the average percent occupancy rate as identified by survey respondents.) If state respondents provided their federal matching percentage under Medicaid, that figure was used to calculate state and federal shares of the total. Where matching percentages were not provided, they were obtained from HCFA publications (*Data on the Medicaid Program*).

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[1] Data are available upon request.

A. Small Privately-Administered ICF/MR Facilities

1. Facility Characteristics

Only 17 of the states responding to the survey (40 percent) have developed small private ICF/MRs. Together they reported a total of 256 privately administered small ICF/MRs (less than 16 beds) as of June 30, 1979.[2] Of these 17 respondents, only one — **Minnesota** — has more than 30 privately administered small ICF/MRs in operation. **Minnesota**, the first state to use the ICF/MR program as a major component of its community-based residential system, has approximately 174 small privately administered ICF/MRs in the state. Fourteen of the 17 states, however, have less than 10 small privately administered ICF/MRs in their respective states.

States are predicting significant increases in the number of small privately administered ICF/MRs by 1984. Twenty-one states project a combined total of 1,412 small, privately administered ICF/MR facilities by June 30, 1984—an increase of at least 552 percent over currently reported figures. Six new states plan to develop small ICF/MRs by 1984. These states are **California, Indiana, Louisiana, Maine, Tennessee,** and **Washington.** Moreover, certain states such as **Massachusetts** and **Michigan** plan a significant expansion of their small private ICF/MR network. **Massachusetts,** for example, had only two small private ICF/MRs as of June 30, 1979, but is planning to develop 93 by 1984. **Michigan** had 14 small ICF/MRs as of June 30, 1979, and anticipates having 225 in operation by 1984. Other states like **Nebraska** and **Kentucky** are in the midst of implementing a small ICF/MR program in their respective states, but could not estimate how many small ICF/MRs would be operational by 1984.

2. Bed Capacity

As of June 30, 1979, 16 of the 39 responding states reported approximately 3,898 private small ICF/MR beds currently in existence. Five states reported only eight beds (one facility) and one other state (**Minnesota**) reported 2500 beds (174 facilities). **Michigan** and **Virginia** indicated that not all of their small ICF/MRs were licensed. These uncertified beds were not included in the total. Fourteen of the 16 states reported having fewer than 250 small, private ICF/MR beds in the state. These facilities reportedly range in size from four to 15 beds.

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[2] Two additional states—**Connecticut** and **Hawaii**—are known to have small ICF/MRs, but did not respond to the survey.

Twenty-two of the 39 survey respondents anticipate a total of 13,604 licensed small ICF/MR private beds in operation by June 30, 1981. This figure includes several states such as **Nebraska** and **Kentucky** who could not estimate the number of facilities but projected the number of beds. This figure also does not include **New York** and **New Jersey.** Six states expect to have from 251-500 licensed beds, and six states anticipate at least 1000 licensed ICF/MR beds in small private facilities.

Minnesota, which currently has the largest number of small privately administered ICF/MRs in the country, is projecting an additional 350 community ICF/MR beds by 1981. According to the survey respondent, this could be the last wave of new small ICF/MR residences in that state. The future demand for small ICF/MRs in **Minnesota** is linked to the state's six year plan. As part of this long-range plan, **Minnesota** would like to develop 500 community placements for semi-independent living and move approximately 500-600 clients currently residing in small ICF/MRs into these independent settings. The 600 ICF/MR beds freed up by the move would enable another 600 clients to be deinstitutionalized. This residential plan is predicated on the receipt of additional funds for semi-independent living.

3. Client Characteristics

Not all of the respondents in the 17 states with a small ICF/MR program were able to roughly describe the characteristics of clients in those facilities. Thirteen states estimated that the average percent of clients referred to small privately administered ICF/MRs from public institutions was approximately 53 percent. Twelve respondents provided estimates of client retardation levels as of June 30,1979 for small privately administered ICF/MRs and 11 respondents predicted client levels of retardation as of June 30, 1984. The majority of clients in small private ICF/MRs are reported to be mildly or moderately retarded at present. In the future, the majority of small ICF/MR clients are projected to be severely and profoundly retarded. **Michigan** and **Massachusestts** could not provide an estimated percentage but did note that they are serving primarily severely and/or profoundly mentally retarded persons in their small private ICF/MRs. **Minnesota** indicated that they serve only a small percentage of severely disabled persons while **Alaska** noted that 20 percent of its ICF/MR clients are moderately retarded. Future predictions also include several states, such as **Idaho** and **Maine,** who could not provide estimated percentages of clients with mild/moderate retardation, but who did indicate that most of their small ICF/MR residences would be made up of more severely disabled persons.

Survey respondents were asked to provide estimates of the percentages of clients in each type of ICF/MR who are either non-ambulatory, mobile/non-ambulatory, or ambulatory.[3] Ten respondents estimated the percentage of non-

[3] See definitons in Appendix I.

ambulatory clients residing in small privately administered ICF/MRs. Seven of the ten states responding to this question reported that *no* non-ambulatory clients were being served in their small private ICF/MRs. Thirteen respondents estimated the percentage of mobile/non-ambulatory clients residing in small privately administered ICF/MRs. Nine of the 13 states indicated that 10 percent or less of their clients in their small private ICF/MRs were mobile/non-ambulatory. No appreciable change was projected in the future.

4. Costs

Twelve respondents provided cost estimates for small facilities. These states spent approximately $67.5 million on small privately operated ICF/MRs from July 1978 through June 1979. The federal share was approximately $37.7 million, while the state share was $31.8 million. Only **Virginia** reported a local share. **New York** and **Texas**, two states with a large number of small private ICF/MRs are notably absent from this accounting. Thirteen state respondents were able to provide information on operating costs, or charges per client day, by ICF/MR category. The majority of per diems in these 13 states were between $20 and $60 for small private ICF/MRs. Three states (**Alaska, New York** and **Massachusetts**), however, reported average per diems of over $80. Per diem ranges varied from $52 to $100 in New York to $26.64 to $39.28 in South Dakota.

B. Small Publicly-Administered ICF/MRs

1. Facility Characteristics

A small number of survey respondents indicated that their states either are or will be developing publicly-operated small ICF/MRs. As of June 30, 1979, five of the 39 states responding to the survey operate a total of 66 small public ICF/MRs. The five states are: **South Carolina, Texas, Rhode Island, Ohio** and **North Carolina. Connecticut,** which does operate small ICF/MRs, did not respond to the survey.

Another three states — **Virginia, Oklahoma** and **Louisiana** — plan to operate small public ICF/MRs, bringing the total number of small public ICF/MRs projected to be built by 1984 to 378, a 572 percent increase. The percentage increase in the number of small, publicly operated ICF/MRs is dramatic, but the total number of states participating in this program is less than ten. **Rhode Island** stands out as one of the states estimating a substantial expansion in its small publicly-administered ICF/MR program: from 15 residences in 1979 to 200

by June 1984. **Rhode Island** plans on using institutional employees to staff its small publicly operated faclities. Other states like **Michigan** have considered using state institutional employees to staff their small ICF/MRs but were discouraged by the "above-market" public employee pay/benefit scales.

2. Bed Capacity

A total of 604 licensed beds in small public ICF/MRs were reported in five states. The number of beds in a state ranged from five in **North Carolina** to 319 in **Texas**. The size of facilities in these states ranges from four to 15 beds.

As of June 30, 1984, the number of publicly-operated small ICF/MR beds in these and three other states (**Louisiana, Oklahoma, Virginia**) is expected to increase to 2,582. The number of small public ICF/MR beds in a state is expected to range from 48 beds in **Louisiana** to 900 beds in **Rhode Island**.

3. Client Characteristics

Aside from one state (**Texas**), all of the survey respondents indicate that for both the present and the future, more than 80 percent of the clients in small public ICF/MRs will be referred from public institutions.

The number of respondents providing client characteristic information on small publicly operated ICF/MRs was quite small (four for 1979 and eight for 1984). Three state respondents (**Ohio, North Carolina, Virginia**), indicated they would serve less than 50 percent mildly and/or moderately retarded persons in their small residences.

Very little information was received from respondents concerning mobile and/or non-ambulatory clients in small public ICF/MRs. As of June 30, 1979, three state respondents (**Rhode Island, South Carolina, Texas**) indicated they had no non-ambulatory clients in their small ICF/MRs. **Rhode Island** did, however, note that all of their clients were mobile, non-ambulatory. By June 30, 1984, **Ohio** predicts that approximately 35 percent and 20 percent of their clients will be non-ambulatory and mobile non-ambulatory respectively. Both **Louisiana** and **North Carolina** estimate that approximately 15 percent of their clients will be mobile non-ambulatory by that date.

4. Costs

Only two state respondents provided costs for publicly operated small ICF/MRs. **Rhode Island** estimated that approximately $2,230,150 was spent on small ICF/MRs from July 1978 to June 1979. **Ohio** estimated that $804,825 was spent on public small ICF/MRs during that same time period.

C. Large Privately-Administered ICF/MRs

1. Facility Characteritics

Twenty-four of the 39 states responding to the survey reported 237 large private ICF/MRs (over 16 beds) currently in operation. Eighteen, or 46 percent of these states had from one to ten such facilities, including six states with only one such facility. **Minnesota** reported 51 large privately administered ICF/MRs within the state.

Only 16 of the 39 survey respondents projected the number of large privately administered ICF/MRs for 1984. Several respondents expect no growth in large privately administered ICF/MRs. **New York** did not attempt to estimate the future number of large private ICF/MRs. Other states like **Ohio,** however, expect new growth in this portion of their ICF/MR program — bringing to a total of 70 large private ICF/MRs expected to be operating in their states by 1984.

2. Bed Capacity

There are a substantial number of beds in large privately administered ICF/MRs. Twenty-four of the 39 states responding to the survey reported a total of 14,678 beds, ranging from 35 beds in **Tennessee** to 2,600 beds in **California.** Eighty percent of the responding states, however, reported no more than 750 beds were in this category.

The privately operated ICF/MRs tend to range in size from 20 to 50 beds at the lower end of the scale, but many are as large as 300-400 beds. Some states like **New York** report extremely large differences in their facilities. Facilities in this state range in size from 16 to 612 beds.

Eight of the 21 respondents reported that occupancy rates for their large private facilities ranged from 96 to 100 percent. All but one of the 21 state respondents **(Utah)** indicated occupancy rates of over 86 percent. **Utah** reported an 82 percent occupancy rate. Occupancy rates are expected to remain high in the future. Eight states projected occupancy rates of 90 percent and over.

3. Client Characteristics

The referral rate to large privately administered ICF/MRs from large public institutions is lower than the referral rates for small facilities, averaging approx-

imately 46 percent; the median, however, is only 33 percent (N=17). The mean percent of mildly and moderately retarded clients in large private ICF/MRs (38 percent) was higher than in the large publicly operated ICF/MRs.

Data on privately administered large ICF/MRs serving non-ambulatory and mobile, non-ambulatory clients is limited. Sixteen respondents provided information on the percentage of non-ambulatory clients and 12 provided information on mobile, non-ambulatory clients. The mean percentage of non-ambulatory clients reported in privately administered large ICF/MRs is 23 percent, while the mean percentage for mobile, non-ambulatory persons served in these same facilities is 16 percent.

4. Costs

Respondents in ten states provided cost estimates for privately administered large ICF/MRs. These states spent approximately $107.3 million in such facilities from July 1978 to June 1979. The federal share was approximately $60.3 million, while the state share amounted to $45.9 million. A local share was reported for only one state and amounted to $1.1 million. (Once again, several significant states, such as **New York, Minnesota, Texas** and **Ohio** are absent from this accounting.) For large private ICF/MRs, 11 of the 15 states responding to this question reported average per diems ranging from $30 to $50. Per diem ranges varied from $34.87 to $75 in Kentucky to $20 to $36 in Utah.

D. Large Publicly-Administered ICF/MRs

1. Facility Characteristics

Thirty-seven of the 39 survey respondents (95 percent) reported a total of 221 large public ICF/MRs (over 16 beds) in operation. The number of such facilities in these states ranges from one to 21. The median number of large publicly operated ICF/MRs in these states is four facilities. Twenty-two of the 37 states operate less than five large, publicly-administered ICF/MRs.

Only 27 of the 39 states provided projections for the numbers of large publicly administered ICF/MRs. Some states are projecting growth by 1984 in spite of the fact that many states **(Minnesota, Michigan, Nebraska, Montana, New Hampshire, Pennsylvania** and others) are planning reductions in the total number of state institutional ICF/MR beds. **New York** was not included in these figures, but according to its FY 81-82 plan, the state anticipates a decline in the number of large publicly operated ICF/MRs. It should be noted that for purposes of this survey, large ICF/MRs can mean any residence over 16 beds, but the term

does not necessarily imply huge, 500 bed or more facilities. **Florida**, for example, is limited by regulation to no more than 60 beds in any single ICF/MR facility. In addition, each living unit within a facility in that state must total no more than 15 beds.

2. Bed Capacity

Thirty-seven of the 39 states indicated that a total of 96,899 ICF/MR beds are currently certified/licensed in large public facilities in their states. The range of total certified beds among respondents was 120 beds in Alaska to 16,079 in New York. Nine states have from zero to 500 beds; seven from 500 to 1,00 beds; and 21 states reported having over 1,000 beds. Three states, **New York**, **Pennsylvania**, and **Texas**, have over 7,000 ICF/MR beds in large public facilities.

Publicly operated large ICF/MRs vary widely in size (e.g., from 21 beds to 1,206 beds in **Pennsylvania**, and from 200 to 2,240 beds in **Virginia**). Seven states have facilities ranging from 100 beds to 1900 beds. Another eight states have facilities ranging from 30 to 1,600 beds. Twenty of the 33 respondents indicated that occupancy ranged from 96 to 100 percent in their large publicly operated ICF/MRs. The other 13 state respondents reported that occupancy ranged from 86 to 95 percent.

A number of states, for example, **Oklahoma**, estimate that the same number of beds will be needed in 1984 as were needed in 1979. **Florida** is even projecting a large increase (from 481 to 2,744 licensed beds)[4], while **Ohio** expects to add 19 new public facilities, increasing the total number of licensed beds from 2,769 to approximately 4,000.

Although the number of state respondents willing to project the future of large public ICF/MRs was only 19 — too few to indicate a generalizable trend — a number of the respondents do forsee a decrease in the bed size of their largest institutions. The size of **New Jersey** facilities, for example, currently range from 282 to 1,302 beds. By 1984, the state official predicted, the largest facility would be 750 beds. Similarly, **Washington** anticipates decreasing the size of its largest facility to 584 beds (currently 898). **Rhode Island** hopes to decrease the size of its only publicly operated ICF/MR from 700 to 100 beds by 1984.

Occupancy rates for these facilities are projected to remain high. Fourteen of the 16 states responding to this survey question projected at least an 86 percent occupancy rate.

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[4] Of these beds, 744 will be cluster arrangements consisting of small facilities (15 beds or less), that may or may nt be located on the campus of a larger facility.

3. Client Characteristics

The mean percent of the clients in large public ICF/MRs who are mildly and/or moderately retarded is reported to be 27.4 percent (N = 27). Only four out of the 27 states responding to this question (15 percent) indicated that their large public ICF/MRs serve a population comprised of 40 percent or more clients who are mildly/moderately retarded. Fifteen of the 27 respondents (56 percent) noted that 21 to 40 percent of their clients are mildly or moderately retarded.

In the 12 states venturing to make projections for 1984, the mean percent of mildly/moderately retarded clients in large public ICF/MRs is expected to drop to 13 percent, with a range from 2 to 24 percent. Only one of the twelve states projects that the large public ICF/MRs will have a population comprised of more than 20 percent moderately and mildly retarded clients.

The mean percentage of non-ambulatory clients in large public ICF/MRs was reported to be 17.3 percent (N = 27). Ten of the 27 states reported that between 21 and 40 percent of the clients were non-ambulatory and 17 states estimated that 0 to 20 percent were non-ambulatory.

Only nine respondents provided future estimates. Of those nine, all but one predicted that they will serve more than 30 percent clients who are non-ambulatory in large public ICF/MRs by June 30, 1984.

As of June 30, 1979, the majority of state respondents (20 of 25) reported serving from 0-20 percent clients classified as mobile, non-ambulatory. Few respondents (seven) provided future estimates for mobile, non-ambulatory clients.

4. Costs

Total cost figures for large publicly operated ICF/MRs were provided by respondents in 29 states. Of these 29 respondents, an estimated total of $1.9 billion was spent between June 1978 to June 1979 on public ICF/MRs with more than 16 beds. Roughly $1 billion of this amount was federal funds, and $969 million was state funds. Six states reported local contributions amounting to approximately $14 million. Seventy-five percent of the average per diems for publicly administered ICF/MRs of more than 16 beds fell between $41 and $70. Per diem ranges within some states were significant. For example, per diems in Louisiana ranged from $35.92 to $105.72 and per diems in Massachusetts ranged from $95 to $278.

E. Summary Tables

As evident in Table 1, many states are predicting a significant increase in the number of small privately-administered ICF/MRs by June 30, 1984. A similar pattern is also found in the small publicly-administered ICF/MRs. Some states are also predicting increases in both their large public and private ICF/MRs. These new facilities, however, do not necessarily represent large institutional settings (i.e., 1000 beds), but can include any facility over 16 beds as defined in the survey. Many of these new facilities, including small and large ICF/MRs, will be new construction and/or substantial rehabilitation, indicating a significant amount of capital investment by each state sponsoring such development in the next few years.

TABLE 1. Number of ICF/MR's By Type

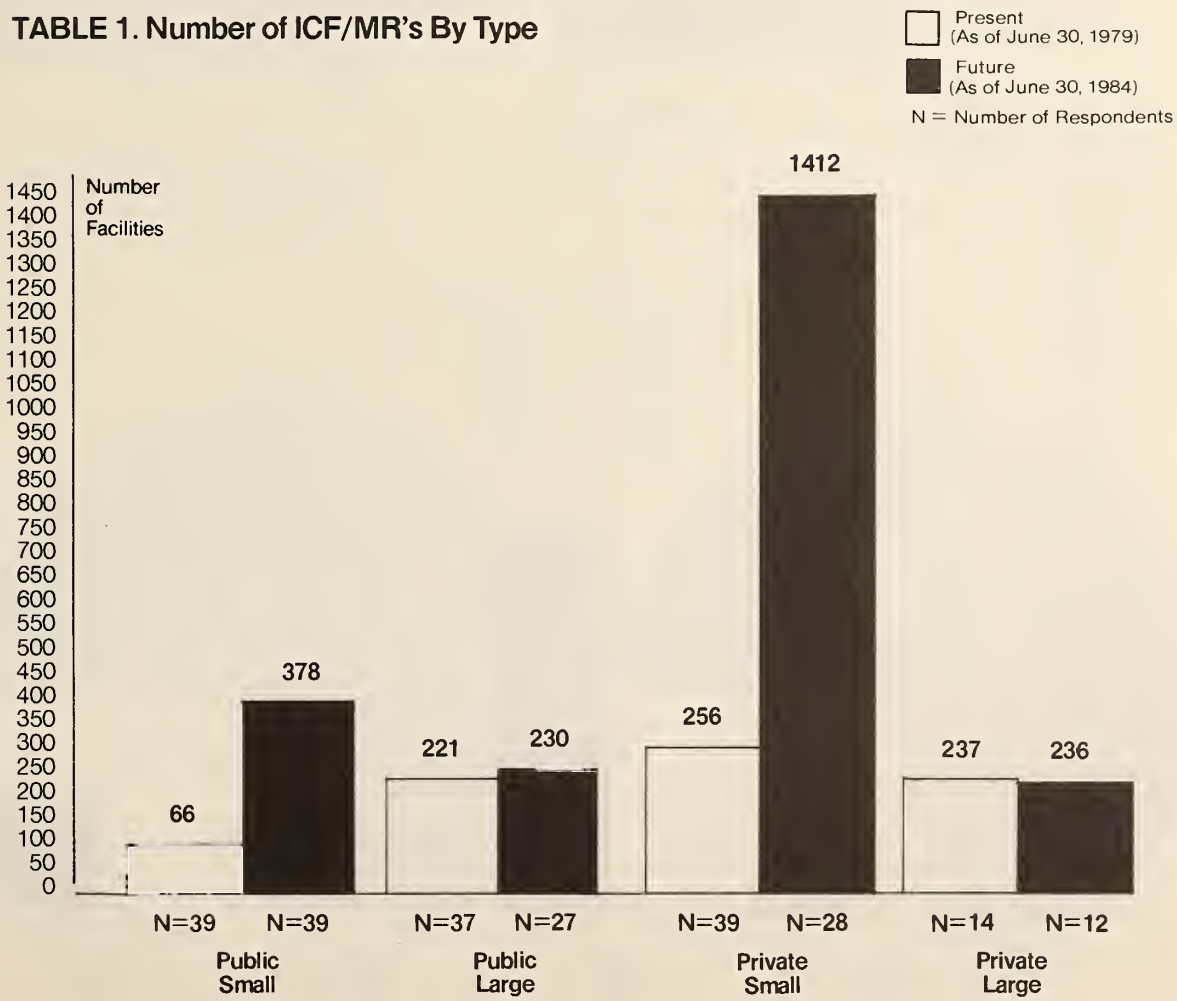


Table 2 provides the reader with the total amount of licensed/certified beds for each ICF/MR category. Although not displayed, the range of beds within each ICF/MR type should also be described. Whereas large public ICF/MRs range from 17 beds (**Maine**) to 2,240 beds (**Virginia**), large private facilities range from 16 beds (**Florida**) to 612 beds (**New York**), indicating that large private ICF/MRs are somewhat smaller as compared to large public ICF/MRs. For instance, at least nine states (**California, Maryland, New Jersey, New York, Oregon, Louisiana, Pennsylvania, South Carolina** and **Virginia**) have large public ICF/MRs of over 1000 beds.

Within small public and small privately-administered ICF/MRs, there is no discernable trend in terms of size of facility. However, by June 30, 1984, **Texas** expects to increase the minimum size of its small publicly operated ICF/MR from four beds to eight beds. Given the anticipated demand for small community residences during the next decade, many states may not be able to restrict the size of small ICF/MRs to six or eight beds as they would like to do. Further, because of the increasing costs of new ICF/MR development, states may be forced to utilize fewer facilities, thus increasing the number of beds in each facility.

TABLE 2. Number of ICF/MR Beds By Type

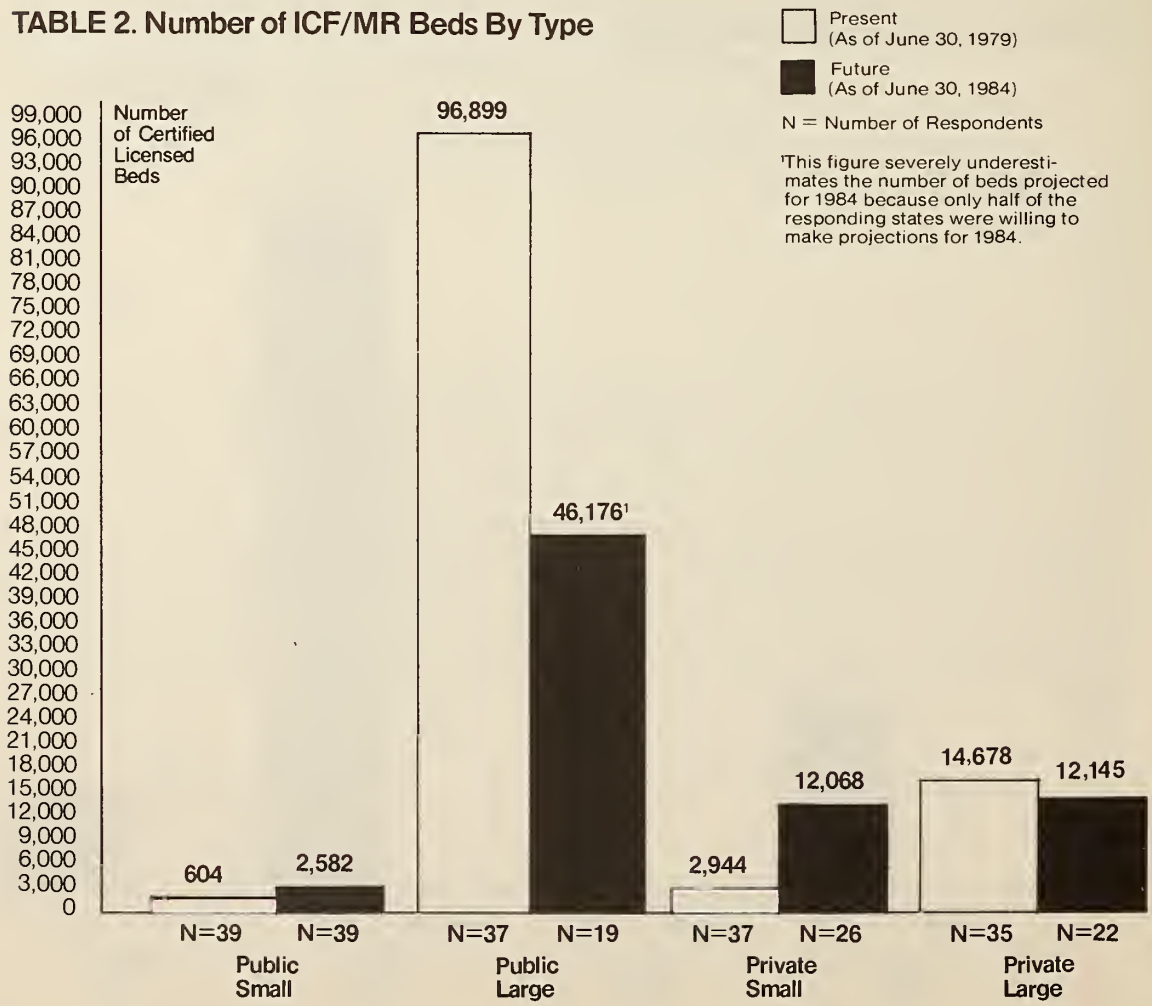
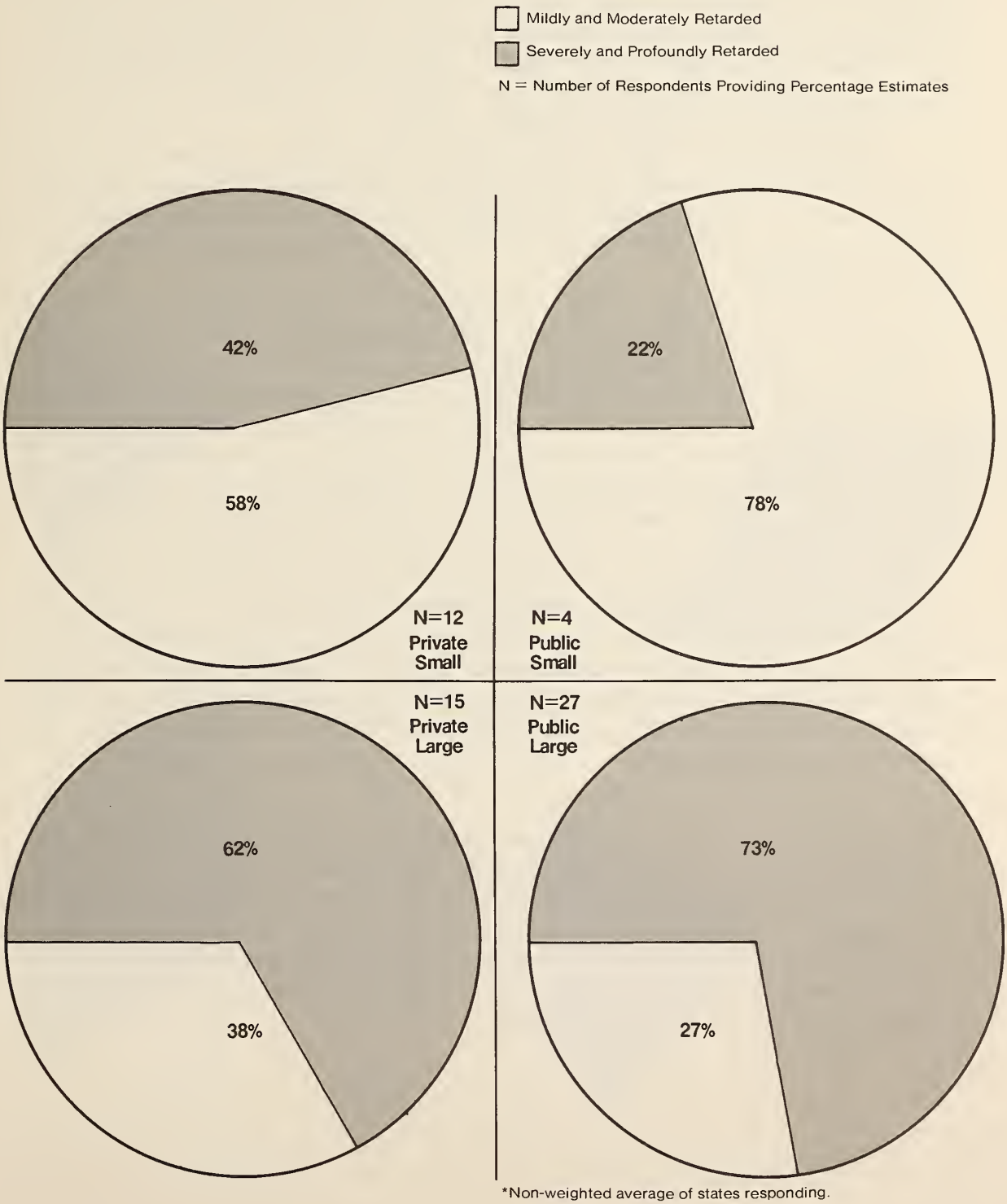


TABLE 3. Average Percent Mildly and Moderately Retarded vs. Severely and Profoundly Retarded By ICF/MR Type as of June 30, 1979*



*Non-weighted average of states responding.

Tables 3 and 4 describe the types of clients currently served in both small and large ICF/MRs. Interestingly, large public and private ICF/MRs are serving more disabled clients than small private and publicly administered ICF/MRs. Of the four states providing estimated percentages in small public ICF/MRs, the mean percentage of mild/moderately retarded clients is 78 percent. Twelve states indicate that 58 percent of the clients served in small privately-administered ICF/MRs are mildly and/or moderately retarded. Twenty-seven states noted that an average of 27 percent of the clients served in large public ICF/MRs are mildly/moderately retarded and 15 states noted that 38 percent of the clients in private ICF/MRs are mildly/moderately retarded.

Although very few states could predict with confidence the percentage of clients who would be mildly and/or moderately disabled by June 30, 1984, the trend appears to be that small private and public ICF/MRs will increasingly be serving more disabled clients as they receive more and more clients from large public institutions.

In terms of clients' mobility characteristics, large public and private ICF/MRs appear to be serving a few more non-ambulatory and mobile, non-ambulatory clients than small public or private ICF/MRs. For example, 17 percent of the clients in 27 states providing information for large public ICF/MRs are non-ambulatory and 17 percent are mobile, non-ambulatory. Ten states noted that 15 percent of their clients in small private ICF/MRs were non-ambulatory. The average percent is misleading, however, since there were so few states responding and the range of cases is extreme. For example, among the ten states providing information on small private ICF/MRs, seven noted that no (0 percent) clients were non-ambulatory, while 90 percent of the small private ICF/MR clients in one state (**Nevada**) are non-ambulatory. A similar pattern can be found among those states providing information on clients who are mobile, non-ambulatory in small publicly-administered ICF/MRs. It should be noted that the remaining clients not identified as non-ambulatory should be classified as ambulatory. This does not mean, however, that all of the ambulatory clients are capable of self-preservation.

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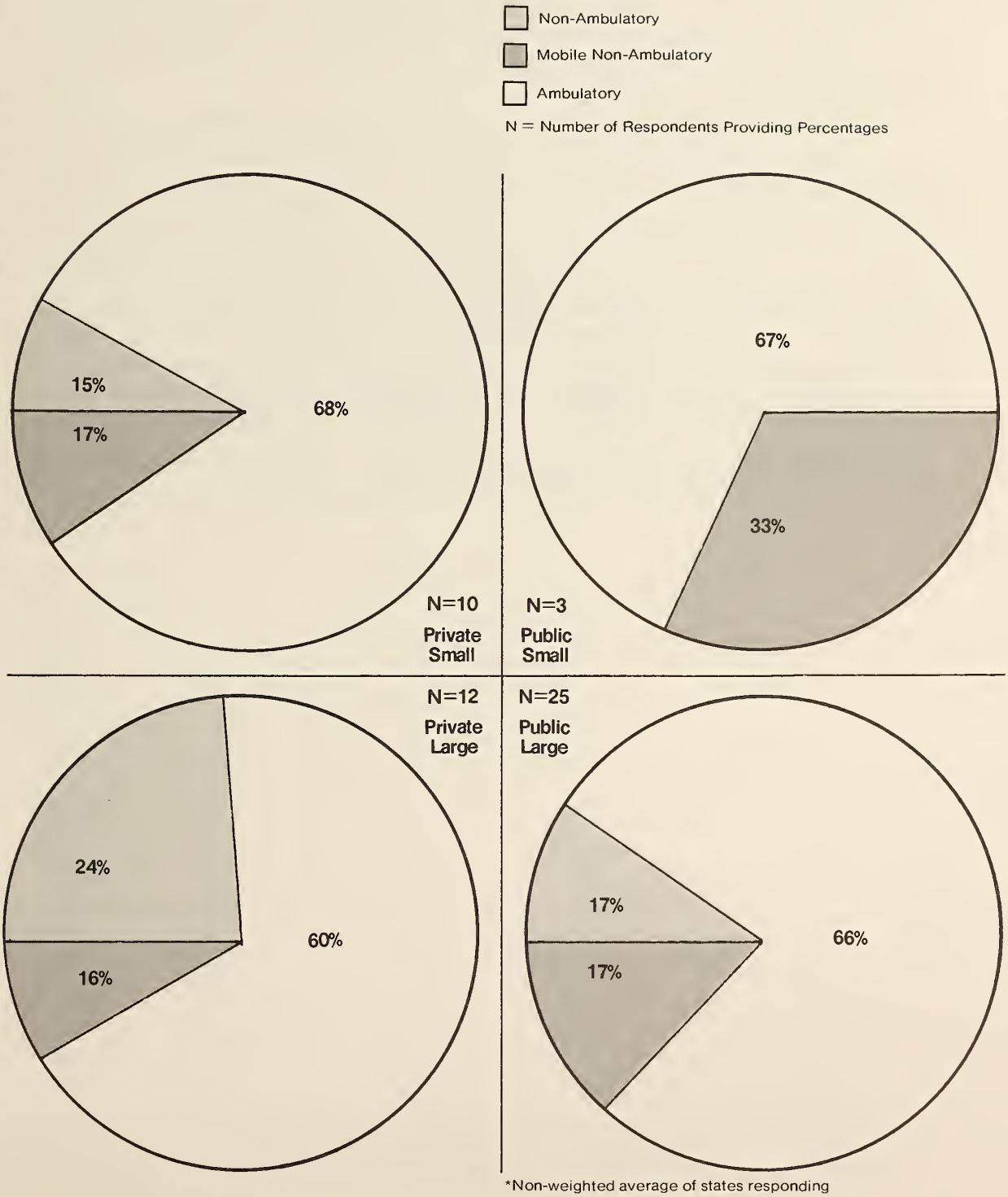
*States were asked to provide the estimated percent of non-ambulatory and mobile non-ambulatory clients residing in ICF/MR facilities. For those states providing an estimated percent, an average percent was calculated for non-ambulatory and mobile non-ambulatory respectively. With the exception of small publicly-administered facilities, only those states providing estimated percent for both non-ambulatory and mobile non-ambulatory were included in the total. The average percent is equal to the sum of each states percent divided by the number of states responding.

TABLE 4. Average Percent Non-Ambulatory, Mobile Non-Ambulatory, and Ambulatory Clients*



*Non-weighted average of states responding

Tables 5 and 6 describe the average per diems and the range of per diems by ICF/MR type. Although there is not a wide range in the average per diems provided by type of ICF/MR ($55 for small public; $59 for small private and $44 for large private), large public ICF/MRs continue to receive higher average per diems than any other category of ICF/MR facility.

Twenty-four of the 32 states providing information on large public ICF/MRs indicated that their average per diems fall between $40 and $70 whereas ten of the 13 states providing information on small privately-administered ICF/MRs have per diems ranging from $20 to $55.

In terms of total operational costs requested from the states participating in the survey, total figures for each type of ICF/MR facility were presented in the previous sections. Since the same states did not respond to all questions, it is difficult to accurately compare the costs of one type of ICF/MR with another. However, nine states were able to provide rough estimates of their operational costs for both large public ICF/MRs and small privately-administered ICF/MRs (**Alaska, Florida, Idaho, Michigan, Montana, Ohio, Oregon, South Dakota** and **Virginia**). It should be noted that several of these states have only one small privately-administered ICF/MR. Nevertheless, for those states, in FY 1979, approximately $335,252,494 was spent in large public ICF/MRs whereas only $31,326,814 was spent in small privately-administered ICF/MRs.

By taking this estimate, it appears that the overwhelming majority of ICF/MR funds continue to be spent in large public institutions.

TABLE 5. Average Per Diems By ICF/MR Type as of June 30, 1979

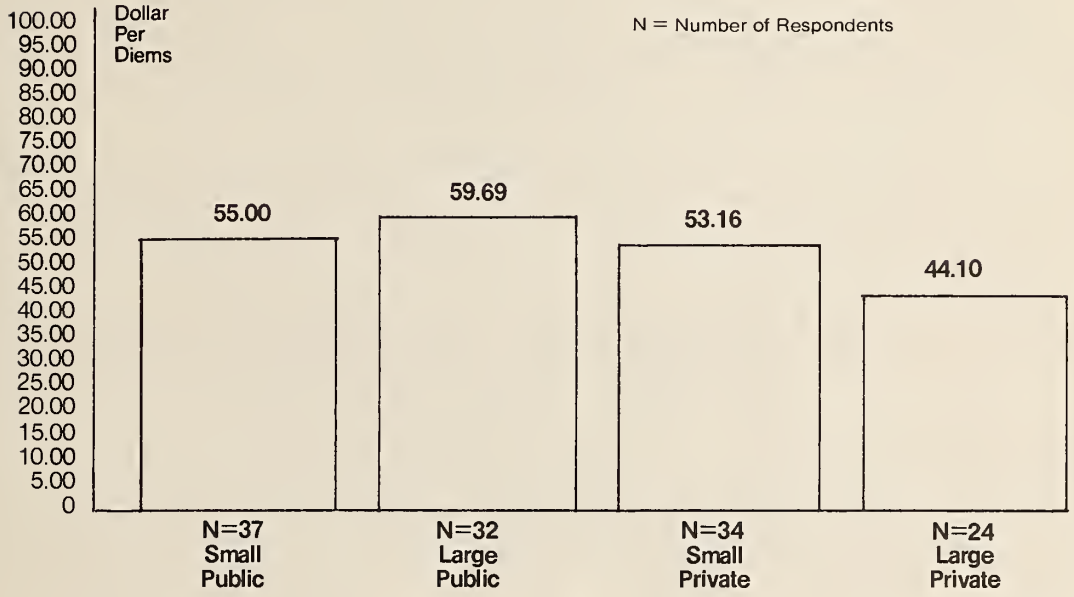
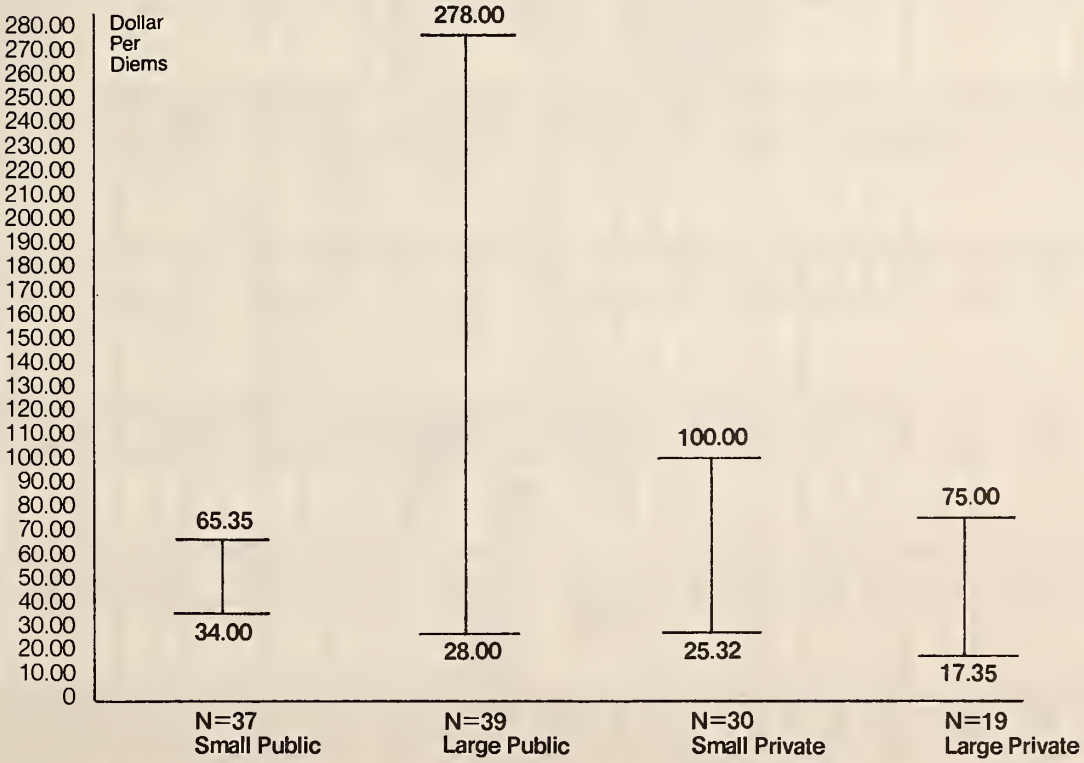
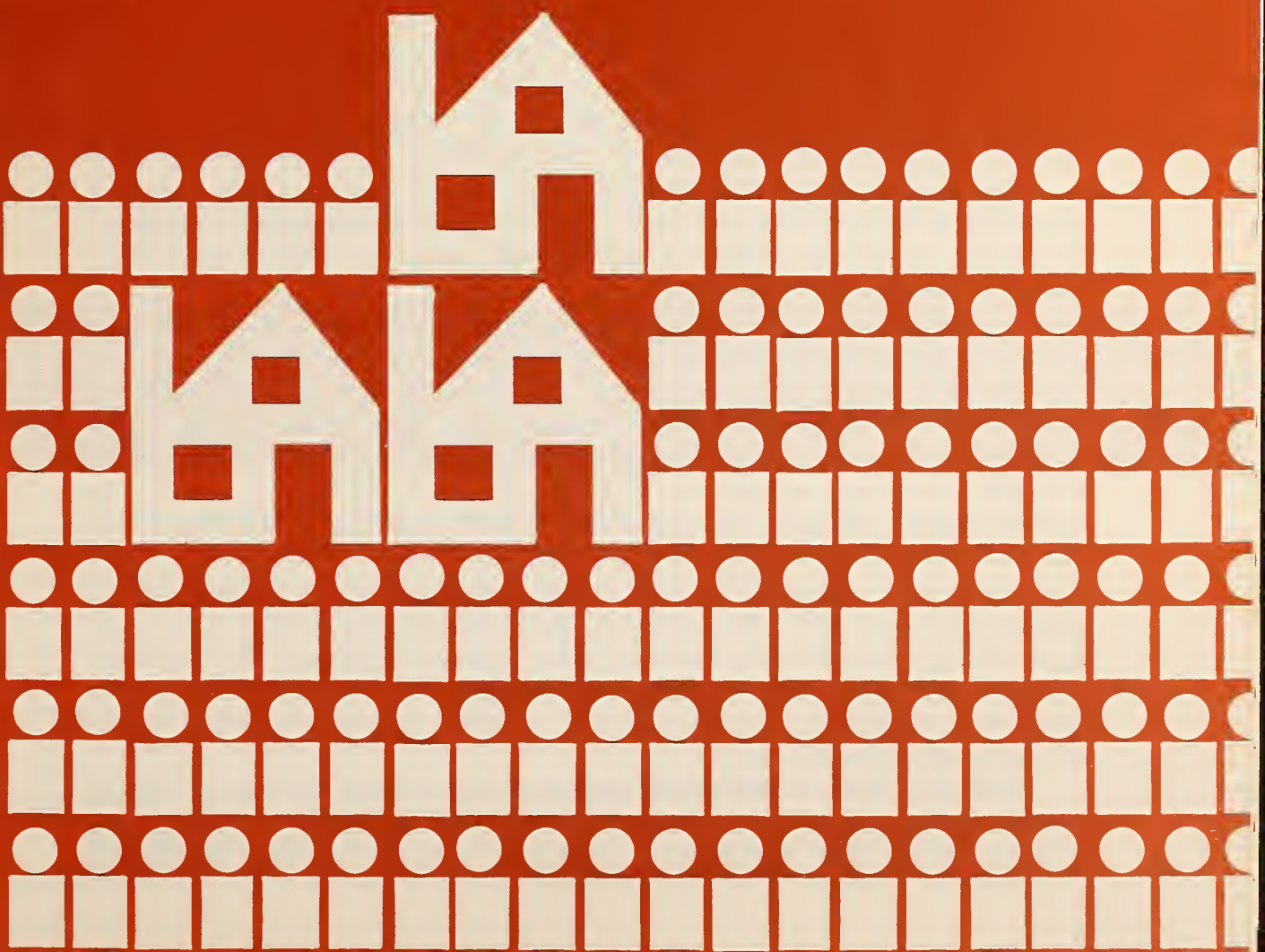


TABLE 6. Range in Per Diems By ICF/MR as of June 30, 1979



III. POLICY IMPLICATIONS FOR THE FUTURE DEVELOPMENT OF ICF/MRs



I. QUALITY ASSURANCE

A. Surveying, Licensing and Certification

Survey and certification procedures for large and small ICF/MRs varied from state to state. Most state officials indicated that their licensing and certification procedures generally follow federal guidelines for ICF/MRs. For these states, the MR/DD agency has either a limited role or "no role what-so-ever" in the survey and certification process. Other states report they have established additional standards and requirements for ICF/MRs. These requirements may or may not be more restrictive than the federal standards. When the MR/DD agency does participate in the survey and certification process, it is generally to assure that all facilities meet additional minimum state criteria established by the MR/DD agency. Consequently, the MR/DD agency has licensure responsibility prior to survey and certification by the health department (e.g., **Ohio, Rhode Island, Alabama**), or conducts additional review and approval procedures for small facilities (e.g., **Colorado, Minnesota, Michigan**).

In **Rhode Island**, for example, the Department of Mental Health, Retardation and Hospitals has developed licensure standards for ICF/MRs, that must be complied with before the Health Department can survey and certify. Officials in the MH/RH Department in Rhode Island, however, are trying to eliminate this latter process because their licensure standards are less stringent than the federal ICF/MR standards. Instead, the MR Division in Rhode Island is trying to establish responsibility for endorsing all ICF/MR programs. In addition to the MR Division's licensure responsibilities, officials in that department noted that they are trying to establish a monitoring and evaluation unit to develop program standards for small ICF/MRs that adhere to normalization principles. These standards will be related to program rather than licensing issues, and will emphasize quality of life issues. They will address such questions as, "Is it a place where you would want your son or daughter to live?"; "Does the bedroom reflect the individual's personality?"; etc.

Small ICF/MRs in **Minnesota** also must meet certain Division of Mental Retardation programmatic criteria/standards before the facility is licensed and certified by the State Department of Health. When a provider applies for

ICF/MR funding, this triggers action among three departments/divisions: Health, Mental Retardation and Finance. All three agencies work together in reviewing the application. The Division of Mental Retardation, however, has ultimate control over the approval of any potential ICF/MR provider. This action also applies to agencies desiring to establish residences over 16 beds.

Other states that will be developing small ICF/MR programs in the near future are also contemplating various roles for the MR/DD agency in the surveying, licensing and certification process concerning Title XIX facilities. State officials in **Maine** noted that responsibility for licensing and certification currently rests with the Department of Human Services, an overall cabinet post. The Bureau of Mental Retardation, however, must sign a statement documenting that the proposed ICF/MR residence is programmatically sound before the licensure and certification process for small ICF/MRs is completed.

Other states, including **New York, South Dakota, North Carolina,** and **Colorado,** have either established various responsibilities for the MR/DD agency, or adapted additional standards applicable to ICF/MRs. In **New York,** the Department of Health has delegated surveying responsibility for community-based ICF/MRs to the MR/DD agency. **South Dakota** has adopted the JCAH AC-MR/DD standards for small ICF/MR facilities—standards that are somewhat more stringent than the federal regulations. In **North Carolina,** all small community ICF/MRs must comply with state group home guidelines, in addition to federal regulations. Officials in **Colorado** noted that their procedures for surveying small and large facilities are somewhat different. For small facilities, Colorado has incorporated additional criteria into their survey which were adopted from models in Michigan and Minnesota (discussed at later point).

B. Client Eligibility Criteria for Small ICF/MRs

Several other states have established additional client eligibility criteria for small ICF/MRs. It appears that there is a wide diversity among the states as to whom they regard as eligible for ICF/MR services. **Texas** will qualify those clients who are in need of transitional living services. Although IQ is a factor in determining eligibility **Texas** also looks at the level of adaptive behavior and other physical and behavioral characteristics. Overall, however, the client must benefit from active treatment. Further, active treatment as defined in Texas regulations can include special education classes and pre-vocational training. As evident in Texas' response to the survey, most of their clients in small ICF/MRs fall into the mild/moderate range of retardation.

In **Vermont,** clients must have substantial programming needs in order to qualify for ICF/MRs. As noted by a Vermont staff person, these clients are more

likely to be in the severe to profound category.

Similarly, **Michigan**'s AIS/MR facilities will serve those residents who have multiple handicaps and/or a level of self-help skill development which requires continued intensive habilitative training and interdisciplinary program services support. Residents who are medically fragile or who have related medical problems that require intensive medical supervision will not be served in AIS/MR facilities.

New York also has developed additional client eligibility criteria for admission to their community-based ICF/MR program. For admission to either a state operated or privately administered small ICF/MR, an individual must evidence at least one of the following several characteristics:

1. A diagnosis of a developmental disability, a health care or other habilitative or rehabilitative need, which is evidenced by a severe or moderate deficit in at least one (1) area of adaptive behavior.

2. A diagnosis of a developmental disability and a severe behavior problem. Such clients shall not manifest a primary diagnosis of mental illness. In the case of an individual who has demonstrated a behavior or behaviors which resulted in injury to other persons, or had the potential for injuring other persons, the review and recommendation is required of an outside consultant committee consisting of at least a psychiatrist, one QMRP psychologist, and one other QMRP. The committee shall include as part of its membership a representative of the provider and a representative of the DDSO. This committee shall consider the following factors in determining the appropriateness of admission.

    a. The client is in need of the highly structured programming which can best be provided at the Intermediate Care Facility, and no less restrictive need-appropriate service exists.

    b. The lack of highly structured programming will result in a probable increase in the incidence of the severe behavior problem.

    c. The Intermediate Care Facility can provide such programming. (The fact that such programming does not currently exist at the facility shall not be the overriding reason for denying admission.)

    d. How frequently these incidents of antisocial behavior must occur in order for an individual to be judged appropriate for ICF level of care depends to some extent on the severity of the problem and its history, but generally, incidents which occurred more than two years ago should not be used to justify admission.

An Intermediate Care Facility may impose more restrictive admission policies with approval of the Commissioner, to allow it to focus its services on a specific

set of health, habilitative or rehabilitative needs of the developmentally disabled (e.g., agency wishes to deal primarily with developmentally disabled individuals evidencing severe behavior problems). However, admission may not be limited to a specific diagnostic population of the developmentally disabled.

Upon admission to the Intermediate Care Facility, a Level of Care Eligibility Determination shall be completed for each client in the form and format prescribed by OMRDD.

C. Administration/Management

At least five state MR officials noted that they have good working relationships with their state health departments (**Virginia, Ohio, South Carolina, Colorado, Illinois**) concerning their survey and licensing process.

Virginia, for example, has worked with its health department to train health department surveyors in the area of developmental disabilities.

In past years, the Ohio Department of Health contracted with the MR/DD agency to do program surveys. Although the health department severed this contract as of January 1, 1980, they have not yet been able to hire someone to complete the surveys. As a result, the MR division is still participating in these surveys, and anticipates that it will continue to do so in the role of consultant. In addition, the Ohio Department of MH/MR and the Ohio Department of Public Welfare have entered into an interagency agreement to provide the maximum amount of coordination in the delivery of medical care and services to mentally retarded individuals that are hospitalized or institutionalized under the Title XIX program.

In **Illinois,** certification is done by the Department of Public Health. The Department of Mental Health, however, is working with Public Health to establish an interagency agreement concerning utilization review and quality assurance. Under this agreement, the Mental Health Department will actively participate in the IPR and UR survey, and the Public Health Department will have the final sign-off.

In **Colorado,** the Division of Developmental Disabilities must first approve each ICF/MR application for less than 16 beds before it is forwarded to the Department of Health for certification. Further, the Division has its own survey team consisting of Central Office staff and representatives from around the state who survey small ICF/MR residences in addition to the Health Department. The two agencies have developed a close working relationship and Health will not issue a license without the Division of DDs prior approval. The Divison's survey team uses a checklist which has incorporated elements from the Program Analysis Service System (PASS) and criteria developed in **Michigan** and **California** to review each small ICF/MR. The Division's survey is completed in one day and

their findings are then sent to the provider with a timetable for making improvements.

States with limited participation in ICF/MR surveys and certification noted that their roles are usually in the form of technical assistance. For example, in **Wisconsin,** the Bureau of DD is only involved in reviewing the program statement for a facility. In **Florida** the Developmental Services Program Office does not participate in the survey or certification process except in technical assistance, monitoring, planning, and policy making for ICF/MR programs.

D. IPR and Utilization Review

Approximately 11 state officials indicated that IPRs and URs were generally ineffective and inefficient. This mainly stems from the review teams' lack of appropriate skills concerning developmentally disabled persons and their orientation toward the nursing home, medical model.

A recent report prepared by the MR/DD Division in **INDIANA** summed up the problem as follows:

"Nursing homes which have mentally retarded people and ICF/MRs are too frequently licensed and monitored by agencies and persons lacking necessary familiarity and expertise in the area of mental retardation. Typically, the surveyors are not trained in the developmental model nor oriented to the developmental process. Therefore, state surveyors and evaluators know little of current methodologies, technologies, or advancements in the field of mental retardation. They often know even less about how these processes might be implemented. In fact, their main training is in the medical aspects of human service."

Many state officials consistently expressed the sentiments noted above. One state official related a story to illustrate his point.

A physician on the review team did not want to classify a client for the highest level of care because he said the client was too dumb to have that amount of money spent on him. He rationalized that his own son at Harvard doesn't receive that much money!

Another state official referred to the IPRs as "cattle calls" — four unqualified people enter a facility, shake hands, round up the clients, ask their names, shake their hands, and leave. In essence, they said it is perfunctory and ineffective.

On the other hand, approximately 14 state officials noted that IPRs and URs were somewhat helpful, although at least seven states qualified their statements by emphasizing that they are often too concerned with documentation and the medical model. Where IPRs and URs were viewed positively, it was mainly due to the participation of persons trained in MR/DD on the review team. In **Virginia,** the health department has trained surveyors in developmental disabilities. In **Washington,** developmental disability specialists are a part of the utilization review team. In **North Carolina,** all ICF/MR certification team leaders have been employees of the mental retardation centers.

E. Information

At this time, very few states have developed specialized management information systems specifically applicable to the ICF/MR program. The MMIS has not proved to be useful for gathering data on ICF/MRs. **Montana,** for instance, noted that the system is not applicable to the MR/DD population.

Several states, however, have developed a general system that tracks all MR/DD clients in the state. **Texas,** for example, utilizes a modified version of a behavioral characteristics progression which computerizes all MR/DD clients' progress. **Florida** utilizes a client information system which maintains complete data on every client in the state in such areas as client progress, and habilitaton plan information systems. **Oregon** also is looking to develop a computerized statewide client assessment and tracking system, as well as putting results of the IPRs on a computer. **Minnesota** has been able to generate client specific data, including clients in ICF/MRs, through its Minnesota Developmental Programming System.

A. Current Exemplary Programs

Michigan, Minnesota and a few other states have been recognized as developing "model" small ICF/MR programs. Implementation procedures for **Michigan**'s small ICF/MR program, known as the Alternative Intermediate Services for the Mentally Retarded (AIS/MR) were published in December, 1977 and are still operative. The AIS/MR program serves mentally retarded persons (or persons with related developmental disabilities) who are in need of intense habilitative training, 24 hour supervision, and active treatment in a community setting. The program is composed of residential facilities of less than 12 beds that provide ICF/MR services to clients in conjunction with **Michigan**'s Regional Centers for Developmenal Disabilities.

AIS/MR clients receive the same services as those provided to Regional Center clients, however, AIS/MR services are procured from community based generic providers primarily under the auspices of local community mental health boards.

Clients in AIS/MR residences are the responsibilities of the State Department of Mental Health and the local AIS/MR administrative unit. These units are attached to various Regional Centers for Developmental Disabilities and perform five basic functions: 1) residential alternatives development; 2) case management; 3) clinical supportive service and/or technical assistance 4) billing coordination; and, 5) internal coordination. The AIS/MR units are also responsible for site and program development. This includes contacting builders and potential investors who may want to invest in community residential development.

Private investment has spurred the development of small ICF/MRs in **Michigan**. The use of private investment is advantageous to both the state and to private investors. This arrangement enables the Department to hold ten year leases with each private investor and at the same time, allows the private sector to invest in property as a tax shelter. The Office of Management and Budget executes and oversees the lease arrangement with the private organizations.

AIS/MRs may be operated by Community Mental Health Services Board staff, non-profit specialized housing groups, or by proprietary organizations. AIS/MR providers are encouraged to contract for three to six facilities, and/or a total of 30 to 50 beds. Any contract that will cause a single corporation's total capacity to exceed 100 beds will require the approval of the ICF/MR project

manager. In addition, a single corporation may sign a maximum of eight contracts to operate AIS/MR facilities. These facilities are licensed under the Adult Foster Care License Act, or the Child Care Organization Licensing Act.

Colorado, like **Michigan** and **Texas,** has taken advantage of private investments to stimulate the new construction of small ICF/MRs. An arrangement was developed with a large west coast investment firm to sell certificates totaling approximately $17 million. Six investors purchased the certificates which will enable the Division of DD to build 32 small ICF/MRs in the next two years; each residence will be leased back to the state. These small residences will be satellites of the State's Regional Centers.

In **Colorado,** 22 private non-profit Community Services Boards (CSBs), are responsible for approving any program concerning developmentally disabled persons in the state. Prior approval by the CSB is mandatory for any provider interested in applying for ICF/MR funds. If an application is approved, the Division of Developmental Disabilities enters into a contract with each CSB which subsequently enters into a subcontract with the actual provider.

For several years, start-up funds were not available in **Colorado** to develop ICF/MRs in the community. During this past fiscal year, however, the State Legislature's Joint Budget Committee allocated start-up funds for 100 small ICF/MR beds. Approximately $1,500 is available for each ICF/MR bed. As a result, a new ICF/MR provider with up to eight beds may receive $12,000 for start-up expenses.

The Division of Developmental Disabilities monitors small ICF/MRs by employing one staff person full time to survey the small residences together with a team of interested persons from different regions in the state.

Minnesota, currently funds 174 small ICF/MRs. Beginnning its program in 1976, the Division of Mental Retardation, within the Department of Public Welfare, stimulated the development of small ICF/MRs by providing direct technical assistance to potential providers under a federally funded project. This project provided technical assistance to small ICF/MR providers at a time when no other state in the country had any experience developing small ICF/MRs. The technical assistance team acted as a resource on all issues concerning development, financing, certification and licensing of small ICF/MRs.

In **Minnesota,** all small ICF/MRs must be licensed under Rule 34, before the ICF/MR can be certified by the Department of Health. This rule is a program license developed by the Division in 1971 for any facility providing residential or domiciliary care services for mentally retarded persons. In addition, each individual client must be determined to be in need of the type of ICF/MR service to be delivered in a small group home.

Minnesota's small ICF/MR program is managed at the county level where county welfare workers perform case management functions. Final sign-off and approval of ICF/MR applications rests with the Division of Mental Retardation.

Several other states will utilize innovative procedures as they proceed to develop small ICF/MR programs. **Maine,** for example, will provide programmatic assistance to potential providers who desire to establish small ICF/MRs.

The Bureau of Mental Retardation will pay a portion of the development costs to get the residence underway. These pre-development costs will be paid through state grants and will help defray some of the costs for the certificate of need application, preliminary architectural plans, and lawyers' fees.

Rhode Island is currently operating a small ICF/MR program, however, state officials noted that this program will be expanding. For its 20 new small ICF/MRs, the Division will hire one person to administer 12 homes with four persons in each home. As a result, each administrator will be responsible for 48 persons. This administrator will be paid a higher salary because of the additional residences he or she will have to oversee. Live-in staff, houseparents, will continue to provide the day-to-day supervisory services for the clients in each home, while supportive services, i.e., social worker, physical therapist, occuational therapist, psychologist, will be shared among the 12 homes. Officials in **Rhode Island** have found this administrative system lowers costs. For example, officials noted that one provider operating one home for children charges $60 per diem, while another provider, who operates five homes, experiences per diems that are approximately $35. Both providers render services to similar client populations.

B. Future Plans for ICF/MRs—State Specific

With the exception of a few states, almost all states contacted were at some stage of development for small ICF/MRs. The stages of development varied considerably from state to state. This section will capsule where several states are today in terms of small ICF/MR development.

Illinois

The Governor's Rate Review Board has approved the development of small ICF/MRs (15 beds or less) in this state. Officials indicated that the facilities will probably average approximately eight beds. The rate that has been established is $36 a day, which includes capital costs, program costs and staffing costs. The Department of Public Health also has submitted draft rules for licensure and regulation of small ICF/MRs.

The executive branch in Illinois has not appropriated funds for capital construction of new ICF/MRs. As a result, the state is purchasing existing four bedroom homes.

Louisiana

Louisiana currently has sixteen privately administered, residential facilities for the mentally retarded that are solely state funded at a total annual cost of approximately $1,720,533. The state is now looking to expand its residential program, and at the same time save state dollars through use of the ICF/MR option.

As a result, state officials are now meeting with consultants from Michigan and New York to study those states' ICF/MR programs.

Kentucky

Officials in Kentucky's MR division noted that they are in the process of working on the development of state regulations for small ICF/MRs. They have not yet received a firm committment on funding from the Bureau of Social Insurance. Three private vendors, however, have been issued a certificate of need. In addition, the State Health Plan in Kentucky has called for 600 beds of "Model B" type facilities (15 beds or less).

Maryland

Officials noted they were planning to develop small ICF/MRs. The Department of Health and Mental Hygiene has been working with Medicaid officials concerning this issue. A joint task force has been created and will make recommendations to the next legislative session (January).

New Hampshire

Officials indicated that they would like to develop small ICF/MRs, but are waiting both for their legislature to give some policy direction, and for a decision on a class action suit pending against the state.

Utah

Utah officials stated that they are in the process of bringing in the Director of NASMRPD to assist them with developing preliminary plans for small ICF/MRs.

Tennessee

Tennessee is in the process of developing small ICF/MRs. These facilities will be sponsored by private non-profit organizations. At the time of the interview they anticipated developing 84 beds to be distributed among eight homes. The range of beds will be from 6-12. Each home will offer a different level care, ranging from intensive care to a less restrictive environment.

Washington

Officials in Washington noted they are in the preliminary stages of developing small ICF/MRs. The state received four proposals at the time of the interview, and a certificate of need has been awarded for one.

California

On July 17, 1980, Governor Edmund G. Brown Jr. signed Assembly Bill 2845. This legislation gives the Department of Developmental Services authority to develop a system of small, 15 beds or less, intermediate care facilities program which will offer primarily habilitation services for persons with special developmental needs.

A new category of state licensing is established. Regulations under which intermediate care facilities are currently licensed are oriented toward providing skilled nursing services. All existing ICF-DDs are large and institutional in nature and the staff in these facilities concentrate more on medical care rather than on habilitation and developmental needs.

AB-2845 mandates that the Departments of Developmental Services, Health Services, and the Office of Statewide Health Planning develop and implement licensing, Medi-Cal and construction regulations to assure that persons with special developmental needs will have appropriate development and health services, in the least restrictive environment, with maximum use of community services, and that licensing and certificate of need fees are set to encourage the development of new facilities.

Two million dollars have been appropriated with this legislation. This money will provide community placement for clients in state hospitals who have been identified by the Department as being appropriate for placement in a small, residential, intermediate care facility.

The Department will allocate a portion of the $2 million to develop small intermediate care facilities and expend other funds for development of community programs including independent living for persons with special developmental needs.

C. Role of Compliance Plans in ICF/MR Development

The majority of officials noted that their state institutions would not meet the July 1, 1980 deadline for compliance with standards set forth in the federal ICF/MR regulations. The majority of these states are either in the process of receiving an extension until July, 1982, or already have been granted a waiver until that date.

The single greatest obstacle to meeting this deadline results from the physical plant requirements of the ICF/MR regulations. Although fewer staes mentioned "staffing problems" as their major difficulty in complying with federal regulations, many states did mention problems in this area as well.

Because most states have been involved in formal deinstitutionalization efforts for several years, it is unclear whether or not state compliance plans are directly tied to community residential development. In some states, officials were absolutely clear that the development of small ICF/MRs was directly tied to the state's compliance plan (**Florida, Illinois, Michigan, New Jersey, New Hampshire,** and **Vermont**). In other states, deinstitutionalization was already underway and officials stated that compliance plans were more of a side issue and had little direct impact on the development of small ICF/MRs.

Other state officials noted that their compliance plan served to upgrade and maintain their state institutions (**Montana, Wisconsin, Texas**) as well as develop residential facilities. **Montana** also noted that the compliance plan stimulated movement to regular nursing homes and regular group homes, rather than ICF/MRs. They also noted that the greatest effect on community arrangements was mainly due to their deinstitutionalization movement. **Washington** also

related their general deinstitutionalization policy as a major factor in the development of residential arrangements.

D. Certificate of Need

The certificate of need process has proven to be a burden to small, community ICF/MRs. This is attributed to the long and complicated process that is associated with CON applications rather than denial of those applications.

Two basic problems associated with CON were expressed by state officials:

- The criteria developed for CON are not suitable for ICF/MR facilities. They are more suitable for health and medical services. In addition, HSAs and SHPDAs are not familiar with ICF/MRs and therefore cannot judge them appropriately.
- The CON process is extremely time consuming. In **Vermont** for example, it takes 150 days at the minimum to get through the entire process. In **Florida**, it takes 141 days to receive a certificate of need. By the time approval is received, interest rates have increased and prices have changed, causing yet another complication in both the ICF/MR development process and the CON application procedure.

Some states like **Texas** and **Colorado** do not require the small, 15 bed or less facility to go through the CON process. The Texas Health Facilities Commission, for instance, has removed their role in the review of these facilities. Other states have tried to shorten the time problem by combining the numerous applications for facilities that are converting into one certificate of need (**Maine**). In **Rhode Island,** the SHPDA is allowing the MR/DD agency to submit a CON for their four-year plan. This has been approved with the stipulation that two years from now, MR/DD must present a progress report.

In a letter to Patricia Harris, Secretary of HHS, the Governor of Florida has asked that consideration be given to waiving CON review for all ICF/MRs and other facility expenditures which are primarily financed and operated by state government. Among the reasons cited for the waiver request by Florida officials are the following: the time consuming process associated with CON review; the fact that many of the ICF/MR projects are simply a replacement or conversion of existing state-owned and operated institutions; the applicability of the CON requirements to review only health services and expenditures when the primary services offered through an ICF/MR are habilitative in nature; and the duplicative nature of the process given the previous executive and legislative review and action taken by elected state officials.

The Commissioner of Ohio's MR/DD Division also has explored many of

the issues related to ICF/MRs and CON in a letter to Janice Caldwell, Director of the Division of Long Term Care, Health Care Financing Administration. Some of the issues cited in the letter include:

- Whether facilities serving MR/DD clients were intended by Congress to be reviewed in the CON process;
- The fact that existing facilities must receive CON approval prior to being certified as an ICF/MR;
- The nature of the review process—HSAs are unfamiliar with ICF/MRs. The letter cited one particular HSA area review meeting where members of the MR/DD Division were invited to provide some background information on ICF/MRs. During the meeting the question was raised, "What is an ICF/MR?"
- The nature of the criteria by which ICF/MRs are reviewed are inappropriate to those facilities.

III. PROGRAM OBSTACLES

By and large, most state officials agreed that the federal ICF/MR regulations tend to constrain the development of small facilities in the community. Most of these problems relate to the difficulties of adapting a small, community program committed to the concepts of normalization to largely medically -oriented service standards.

The following is a list of obstacles that were repeatedly cited by state officials:

- *Recertification of clients' need by a physician every 60 days.*

  According to state officials this seems unnecessary and wasteful. As noted by several states, a mentally retarded client's "condition" is not going to change every 60 days.
- *Initial diagnosis and evaluation is required but not reimbursable.*
- *Requirements for an array of services i.e., QMRP, pharmacist, dietician, etc., that are too costly in a small setting.*

  Approximately 75 percent of the states noted that staffing was a significant problem in small residential facilities. Many believed that the requirements for certain full-time professionals (i.e., pharmacist, Qualified Mental Retardation Professional, dietician, occupational/physical therapist) were unnecessary and too costly for small facilities. This was particularly true in rural areas where there were few qualified health professionals to assume these positions.

- *Fire safety requirements present major problems in development of small ICF/MRs.*

There appears to be a significant amount of confusion and frustration among states concerning the application of Life Safety/Fire Safety code provisions in small ICF/MRs that house mobile, non-ambulatory clients capable of self-preservation, as well as other clients who are either mentally or physically incapable of self-preservation. For example, **Texas** continues to use the institutional section of the 1976 Life Safety Code for mobile, non-ambulatory clients capable of self-preservation even though a U.S. Department of Health and Human Services memorandum in 1978 permits states to request waivers of the institutional code. The Lodging and Rooming House section of the code can be used for mobile non-ambulatory persons capable of self preservation.

Other states, however, (**Michigan** and **Minnesota**), have applied the Lodging and Rooming House provisions of the Life Safety Code (LSC) for those clients who are mobile, non-ambulatory and capable of self-preservation. **Michigan** for instance, has developed guidelines which require one attendant to be on duty at all times for every two non-ambulatory residents in a small ICF/MR. Even though **Michigan** is attempting to use a less restrictive version of the LSC, state officials indicated there are still problems in meeting fire safety and life safety requirements. For example, the requirement for 40 inch doorways; the inability to have basements unless they are closed during the duration of the ICF/MR lease; the required thickness of the dry wall; as well as other technical aspects of the code, all present obstacles in the development of such residences. As noted by **Michigan** staff, new construction is almost always necessary which will directly result in higher costs. (See "Additional Requirements for Non-Ambulatory AIS/MR Facilities Housing 12 or Less Residents," published by the Michigan Division of Community Programs, undated.)

Massachusetts has encountered difficulties in developing ICF/MR residences for clients who are not capable of self-preservation. These residences would include clients both physically and mentally incapable of exiting a building within two and one-half minutes. In order to avoid developing residences with only persons who are not capable of self-preservation the Department of Mental Health, Divison of MR, has proposed a modified group residence (MGR). This home would have a maximum of 12 residents, with no more than eight persons who are not capable of self-preservation. Of those eight, not more than two would be non-ambulatory. If there are more than two non-ambulatory clients, the residence would then have to comply with the more restrictive institutional provisions of the 1976 LSC. In addition, one staff person must be available for each client certified as not capable of self-preservation.

Rhode Island officials also noted that they are experiencing problems similar to those in Massachusetts as they move clients from the institution into the community.

- *Accessibility Requirements—Section 504 and American National Standards Institute (ANSI) standard present major obstacles.*

Several states including **Colorado, Michigan** and **South Carolina** noted difficulties in applying the ANSI standard for accessability to small ICF/MRs. All federally funded facilities, including ICF/MRs, must meet the ANSI standard. Although the ANSI standard has recently been revised to include residential facilities, traditionally, this standard has been oriented toward public facilities.

As a result, many of the design criteria present serious cost and programmatic implications when applied to small community residences. For example, a Colorado Division of DD official noted that ANSI standards require large parking lots and 40 inch wide hallways. In addition, these standards must be applied to apartments as well as to single family homes.

The implication of ANSI and Section 504 are two-fold. First, many of these criteria, such as the parking lot requirement, constrain agency efforts to promote normalization. It is clear, as noted by Colorado staff, which home on the block is occupied by disabled persons from the size of the parking lot outside the home. Second, if all small ICF/MRs are required to meet these accessibility criteria, officials noted that building new facilities may be the only mechanism for meeting these requirements. This clearly implies a tremendous cost problem. Colorado staff have been working with their Department of Health to obtain waivers on a case-by-case basis, if necessary.

- *General Medical Orientation rather than Habilitative Orientation with Medical Support.*

As mentioned earlier, a major problem expressed by all state officials for the future development of residential facilities is the difficulty of adapting a primarily medically-oriented program to the needs of clients who require a more developmental model. This orientation not only adds significant costs to the program unnecessarily, but it lacks the primarily developmental services that are needed by mentally retarded clients.

The Indiana report cited earlier describes this schism between services and needs as follows.

"Intermediate care facilities are primarily health care facilities and tend to be judged by medical standards which are irrelevant to the major needs of most developmentally disabled people. For the most part medical/nursing needs of developmentally disabled persons can be met in the same ways that typical people meet their needs: by health education, adaptive health aids and equipment, private doctors and clinics, visiting nurses, private and public hospitals. For those very few individuals who need to actually live in a health facility full time, 24 hours a day, seven days a week, adequate beds currently exist.

...Regulations demand a high degree of medical intervention since ICF/MRs are a) funded through a federal health care plan administered by federal and state employees who have medical backgrounds, b) surveyed and

licensed by people with medical backgrounds or generalists, c) and operated (usually) under the guiding auspices of health care trained staff. This often results in the provision of health services to mentally retarded persons whose primary need is social and developmental...

... The bottom line analysis reveals the fact that current ICF/MR regulations and standards are fundamentally the outcome of a series of compromises; unfortunately the compromises are of the rights and needs of people who have no voice in the compromise. These compromises have taken ICF/MR standards from being clearly and undisguisedly a totally medical type facility, to what might now best be referred to as a "pseudo-medical" facility, or at best a non-specific facility which has strong medical tendencies..."

The result is often an attempt to fit a "round peg into a square hole," because the type of standards required for the program often do not fit the needs of the client. Consequently, many state officials suggested that either the program standards be changed so that states can attempt to meet deinstitutionalization goals, or that other funding mechanisms be made available so that they can develop programs more responsive to the needs of the client.

- *Requirements that medication must be administered by medical personnel.*

  Some states do not have a certification program for the administration of medication by nonmedical staff.

- *Other problems related to ICF/MR development.*

  A. Funding Issues — For example, the reduction of SSI payment to $25 when the client receives 50 percent of his or her support from Title XIX.

  B. Lack of Start-Up Funds — There was overriding agreement throughout the states that one of the major obstacles to developing community facilities was the lack of start-up funds.

IV. FUNDING

A. Reimbursement Policies

1. Reimbursement and Rate Setting Methodologies

Twelve state officials noted that reimbursement for ICF/MRs is provided on a retrospective basis, while seven states (**Tennessee, Montana, Kentucky, Louisiana, Washington, California and Arkansas**) indicated they utilize a prospective reimbursement methodology. In addition, almost all states utilize a historical based rate setting methodology, adding inflation factors and certain price indexes to the historically based costs.

In general, rates for small and large ICF/MRs are determined in the same manner. However, some states indicated that small facilities could not utilize the historical based methodology since there are no historical costs. In **Vermont,** for instance, rates for small facilities are determined on an actual cost basis, according to an approved budget.

2. Reallocation of Institutional Resources

Most states agree that devastating effects would occur if current federal rules were changed to reduce Title XIX reimbursement rates to large state facilities. They also believe this policy would not necessarily stimulate the development of community residences unless a concurrent increase in reimbursement was applied to community facilities.

Outside of a few states that have already begun to make large investments in community living arrangements and have relatively few institutional beds, most state officials believed that a reduced reimbursement rate would have drastic effects on their state program. The most immediate and dramatic effect would be a major reduction in the quality of care provided at the institutions. In general, the states believed that there would be virtually no means to maintain the standards that have been imposed by the federal government without concurrent federal financial support. Thus, a drastic reduction in services would probably result, along with a few law suits. For those states like **California** and **Michigan** that have made substantial investments in community care, the effect of this policy would be less consequential. In **California** for instance, federal payments are not as important as elsewhere: the state is already pumping $50 million into communi-

ty care, on top of the SSI federal payment.

Despite the predicted disaster for large public institutions, most states were not sure if this policy would stimulate the development of community programs. Some states believed that only a concurrent increase in community reimbursement rates would serve to foster the development of residential arrangements. Yet even in this case, many officials maintained that community care still may not develop. They attributed this prediction to the large sums of money already committed to state institutions, political pressures, permanent overhead costs, and the general feeling that small ICF/MRs are not the only answer given the constraints of the current federal regulations.

An official in **Texas** indicated that their ICF/MR program may be in jeopardy as the federal Medicaid match decreases each year in that state. The official stated that the ICF/MR program is becoming "more hassle for less money" as the federal government is placing pressure on the state agency for stricter standards. He went on to point out that it may get to the point where a 45 percent state match is not worth the trouble, and cause the state to eliminate the ICF/MR program entirely. He noted that this has been a topic of discussion in the state legislature.

B. Alternative Financing

States were asked to comment on funding mechanisms other than Title XIX that are used to support community facilities for the mentally retarded.

Many state officials expressed frustration that they have reached their Title XX ceiling. They believed that this funding stream could be utilized for residential living arrangements, if it was available, and could help develop less intensive models for care. Basically, many officials felt that other community routes would be better suited for this type of care, (i.e., HUD). At this time, however, officials stated that the Medicaid program provides the greatest amount of financial support for care rendered to mentally retarded individuals. The underlying lesson is that the Title XIX ICF/MR program offers a convenient funding mechanism, which provides strong economic motivation for states to participate in the ICF/MR program.

Some states, however, have begun to utilize HUD (Sec. 8) funding to develop residential arrangements for mentally retarded persons.[1] **Tennessee** for example, has worked with their Tennessee Housing Development Agency to build 37 homes. They have arranged with HUD that the homes could be certified as ICF/MRs. Under this agreement, the mortgage is to be paid by Section 8, and the

[1] HUD central office staff are developing a policy on the use of ICF/MR funding to be used in conjunction with their own resources (Sec. 8, Sec. 202).

houseparents are to be paid with Title XIX money. At the present time, they have only received a verbal acceptance, and are awaiting written approval. **Rhode Island** also is becoming involved in HUD housing development. Under this program, between 20-40 slots will be available for MR individuals, and like Tennessee, the mortgage will be paid by Section 8, and Title XIX will reimburse for services. The HUD program will be run by institutional employees.

Virginia also has financed four complexes that are to be certified as ICF/MRs through HUD (Sec. 8) funding. By 1972, they expect to have 135 certified beds under this program. These developments are financed through the Virginia Housing Finance Agency, utilizing Section 8 to repay the mortgage.

V. POLICY COORDINATION

A. Federal Ambiguity in ICF/MR Policy

Within the last two decades, the federal government has consistently urged state and local governments to deinstitutionalize mentally retarded persons. In 1971, for instance, President Nixon proclaimed a national goal to reduce the nation's public mental retardation facilities by one-third within a decade. Almost ten years later, however, and despite the support of successive administrations, there is still no coherent federal policy to assist states in accomplishing this goal.

The Title XIX ICF/MR program typifies many of the problems states have encountered in dealing with an ambiguous federal deinstitutionalization policy. Robert Gettings points out some of these problems in a 1980 issue paper concerning the Title XIX ICF/MR program.

"Despite the fact that a growing number of states have begun to certify small community residences as ICF/MR providers, DHEW has never spelled out a clear, unambiguous policy regarding the desirability of developing such alternatives to large institutional settings, or the circumstances under which such small facilities may be certified as Title XIX providers. As a consequence, states which have elected to take advantage of this option have found that they face numerous impediments—the most significant being the absence of clear federal policy in this area."

One state official expressed similar sentiments in our survey. After extensive analysis, he concluded that the administration of Medicaid from region to region was so varied that he could not make any definitive recommendation to the state legislature concerning whether to follow the lead of other states (e.g.,

Minnesota), or to reject a plan to provide appropriate services in small facilities. He also felt that regional officials did not have enough experience to help states develop small residential programs for mentally retarded persons without guidance from Washington.

Other state officials echoed these statements. Their overriding feeling was that the position of the federal government on small ICF/MRs was ambiguous and unclear, creating many impediments to the certification of small residential ICF/MR facilities as eligible Medicaid providers. At the core, the problem is fairly easy to diagnose — without a regulation defining and setting standards for small ICF/MRs, states must fit their small, residential facilities under standards originally designed for large state hospitals.

B. Health Planning

Another example of the absence of a clear and coherent federal policy and its effect on all states results from the national health planning structure established by P.L. 93-641. This act has, in particular, created problems with the implementation of small, community-based ICF/MRs. These problems have not stopped outright the development of new community facilities. At the same time, however, delays caused by the CON process have slowed deinstitutionalization efforts and have undoubtedly increased construction costs.

The basic problem is an inherent conflict between a comprehensive planning mechanism that has little understanding of mental disability issues and is cost containment oriented, and a deinstitutionalization effort that is attempting to move individuals into new facilities as fast as possible, and is very expansionistic in philosophy. The goals of cost containment and deinstitutionalization are not necessarily antagonistic (indeed, they may be complimentary). The few occasions, however, where health planners and DD officials meet — new construction — is bound to lead to conflicts. Nowhere in federal law, however, has there been an attempt to resolve these apparent contradictions in federal policy. As a result, state and regional officials are left to interpret what few policy statements do exist, and it should not be surprising that they sometimes arrive at different results.

C. New Definition of Developmental Disability

Another example of the lack of a coherent federal policy is the new definition of developmental disability. Current federal law requires that if states offer ICF/MR services through their Medicaid program, they must cover the mentally retarded and developmentally disabled. The expanded definition of developmental disability, however, requires states to cover specific groups such as the learning disabled and the chronically mentally ill, for whom ICF/MR standards were never intended. In addition, few state departments in charge of serving mentally retarded citizens are knowledgeable about or able to serve these new groups of people with developmental disabilities — many have troubles even keeping their own commitments to the mentally retarded.

As a result, many state officials were unsure what effect the new definition of developmental disability would have on their ICF/MR program. Many were worried that the new definition would deluge their program with an unmanageable number of clients. **California,** for example, completed an analysis which concluded that the new definition could potentially increase their population two-fold — adding between 70,000 and 80,000 more people. Still other officials reported they simply were not going to adopt the new definition (e.g., **California, Illinois** and **Oregon**). **California** statutes, for example, specifically exclude the chronically mentally ill from the definition of developmental disability.

In general, many state officials believed they would not know how to handle some of the new groups of clients in the ICF/MR program who became eligible as a result of the new definition of developmental disability. All officials believed the new definition would result in increased costs in the ICF/MR line item. Whether these costs would be offset by savings elsewhere — especially in the budgets of state governments — was not estimated.

D. The Effect of Lawsuits and Court Decrees on the Development of Small ICF/MRs

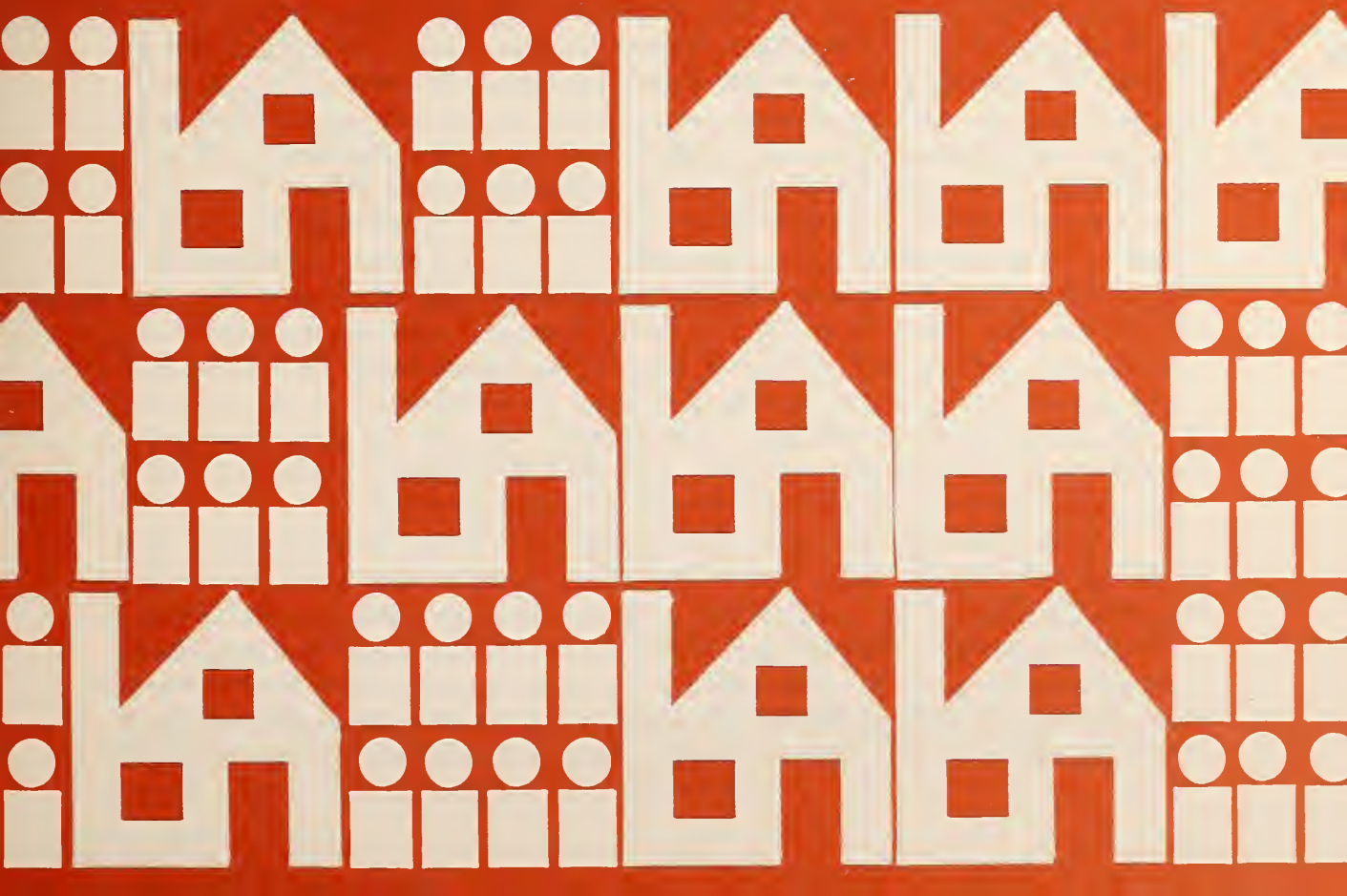
A number of states responding to the survey noted that they were either under a consent decree, in the midst of litigation, or under some type of court order affecting the development of community residences for mentally retarded and other developmentally disabled persons. Some states, such as **Maine,** indicated that as part of their consent decree, the state cannot develop any new residence larger than 20 beds. Existing facilities in that state which are larger than 20 beds, however, will be grandfathered in. In addition, the decree specifies that small ICF/MRs and other community programs must take 50 percent of their clients from the class members (i.e., those currently residing in state hospitals).

In **Nebraska**'s consent decree, the judge strongly urged the development of small community residences. As a result of this judgement, the governor requested that the state Division of MR develop a residential program consisting of homes with 15 beds or less to meet the community requirements under the consent decree.

Many other states, such as **Michigan, Massachusetts, Pennsylvania, New York** and **Rhode Island,** either have consent decrees or court orders dictating that the state government develop a significant amount of community residences, with the emphasis on small, homelike environments. Many of those state officials interviewed indicated that the court rulings have stimulated them to use Title XIX to develop small ICF/MRs.

The future impact of court decisions on the small ICF/MR residential networks is difficult to pinpoint. By implication, however, the Title XIX ICF/MR program will continue to be utilized to develop small residential facilities, because it is one of the few federal financing programs available to meet the demands of the courts.

IV. SUMMARY



In summary, the ICF/MR program continues to pose many burdensome problems for both federal and state officials. Most of the trouble appears to stem from use of Title XIX funds to develop small, community-based ICF/MR facilities. There is much less ambiguity about the use of Medicaid funds in large state institutions that have been substantially renovated to meet ICF/MR standards. Even in the latter area, however, problems with high cost and compliance with federal standards continue to exist.

As the results of this survey of state officials clearly show, the Title XIX ICF/MR program is becoming a significant — some would say the significant — source of federal revenue to implement both state and federal policies aimed at "deinstitutionalization." A few states, like **Minnesota**, already are utilizing ICF/MR monies to fund a significant amount of community care for the mentally retarded. Other states, like **California**, **Massachusetts** and **Michigan**, expect to greatly expand their use of this program in coming years. In the next five years, it is reasonable to expect a nationwide increase of *at least* 500 percent in the number of small ICF/MRs — an estimate that does not include additional potential clients who may be entitled to the service as a result of the new federal definition of developmental disabilities.

Because the ICF/MR program was never envisioned as a major federal deinstitutionalization effort, however, and because its roots are in a medical assistance program designed to upgrade care in large state mental retardation institutions, there are some significant problems with the current federal policy that inhibit the development of small, community-based ICF/MRs. For instance, federal licensure and certification requirements require little or no input from mental retardation agencies, yet impose an array of medical requirements that are costly and sometimes inappropriate and unnecessary. In addition, mandatory utilization review requirements in their current format generally have proved of little value in ICF/MRs. So too, recertification requirements, non-reimbursable initial diagnosis and evaluation requirements, extensive service requirements, and even some life safety and ANSI code requirements have proved costly and sometimes inappropriate to meeting goals of deinstitutionalization, habilitation and normalization. Other problems concern the application of the federally-mandated certificate of need process to the ICF/MR program; ambiguity stemming from the new definition of developmental disability; and variation in regional interpretation of Congressional and departmental policy.

The clear message that emerged from interviews with a large number of state officials was that the federal government has provided little guidance to state governments who utilize the ICF/MR program to engage in deinstitutionalization efforts. State officials believed that few federal offices were capable of conducting technical assistance in this area, and that too many federal officials were concerned solely about meeting the purely medical and cost containment imperatives of the Medicaid program without understanding the needs of the mentally retarded.

Moreover, there was a vague uneasiness among state officials that the entire program, as it stands today, is not the most appropriate method of serving their clients. It is, however, the only readily available source of money and as a result, is expected to be used quite heavily in the future.

The first major policy consideration that should be undertaken is a major rethinking of the entire ICF/MR program itself, i.e., is the ICF/MR program a health program, or should it be funded as some other program? Current statutes and regulations continue to reflect the primarily institutional and medical intent of both the ICF/MR program itself and Medicaid more generally. Doing away with the ICF/MR program's basic status as a medical/health program and recasting the community care portion of ICF/MR as a new program—in line with the social rehabilitative and normalization goals of deinstitutionalization—would eliminate many current problems. For instance, if a small community-based ICF/MR was not considered a "health" facility or funded by a "health" program, it obviously would not have to obtain a certificate of need or meet the structural specifications of a nursing home.

On the other hand, the current open-ended entitlement nature of Medicaid makes it an enormously attractive program for both states and advocates of the developmentally disabled. Enacting a separate non-medical deinstitutionalization program that has the same financial provisions as Medicaid (entitlement plus open-ended) for the same client group may be politically difficult, if not impossible.

Consequently, if the ICF/MR program is to continue to work within the current statutes and regulations, and if it is to proceed in a more rational manner in the future, a number of changes need to be made in federal policy. They include the following:

- Clear differentiation between institutional and community requirements for certification as ICF/MR providers;

- Flexibility in community ICF/MR standards to permit centralized provision of management and staff services to small, community ICF/MR facilities;

- Programmatic and financial incentives to tie both institutional and community ICF/MRs to a comprehensive network of care for the mentally retarded, including both case management and day care;

- Programmatic and financial incentives for state mental retardation agencies to participate in Independent Professional Reviews and Utilization Reviews, as well as licensing and certification decisions;

- Recognition in institutional compliance plans that extensive physical plant renovation may be inappropriate where extensive deinstitutionalization is planned;

- Clear incentives in institutional compliance plans to promote further deinstitutionalization, including development of small ICF/MRs, such incentives might include easing of physical plant standards providing certain numbers of residents are deinstitutionalized; provision of bonus payments for deinstitutionalization; separate funding for start-up costs; etc.

- Improvement in regional office understanding of the ICF/MR program and development of ability to provide technical assistance to states;

- Provision of more technical assistance to mental retardation agencies, Medicaid agencies and community providers concerning the requirements of P.L. 93-641 and each state's applicable certificate of need law, such assistance might include development of model applications; explanations of how some states make exemptions for small facilities; advice concerning how to group facilities under one application; technical assistance on applications for renovation or conversion; etc.

- Flexibility in fire safety and other building code requirements to comport with the needs of residents (this may be provided in a forthcoming report to be completed by the National Bureau of Standards describing a life safety evaluation system for developmentally disabled persons);

- Development of a clear standard concerning how the definition of developmental disabilities applies to the ICF/MR program.

APPENDIX

ICF/MR Survey Background Questions

1. Which agency serves as the single state agency to administer the federal—state Medical Assistance program in your state?

2. Which agency serves as the State Medicaid survey agency in your state?

3. Do you fund the development of small (15 or less) ICF/MRs in the community?

    - If yes, how is the program operationalized?

4. Has the state developed a policy limiting the size of ICF/MR facilities in the community?

    - If yes, please describe.

5. Has the state limited the sponsorship of ICF/MR facilities in the community?

    - If yes, in what ways (e.g., to non-profit or limited individual providers)?

6. What eligibility criteria has the state established for individuals placed in small ICF/MR facilities?

7. What is the role of the state mental retardation/developmental disabilities agency in conducting ICF/MR surveys and ultimate certification (e.g., training surveys, exercising formal sign-offs)?

8. Are any of the procedures used to survey and certify community ICF/MRs different than those used for large facilities?

    - If yes, please describe.

9. Does the state have any additional standards/requirements for community ICF/MRs?

    - If yes, what are they?
    - How do you require that community ICF/MRs meet minimum programmatic requirements for certification?

10. In most states one state agency is responsible for licensure and another for certification under Title XIX. What is the relationship between these two processes for ICF/MRs in your state?

11. Does your Title XIX program provide day services for mentally retarded persons?

    - Does your state certify providers of daytime habilitative services to Title XIX-eligible retarded clients?
    - How do you certify these providers?

12. What, if any, are the major obstacles in the current federal ICF/MR regulations that constrain the development of small facilities in your state (e.g., fire safety standards applicable to community ICF/MR facilities)?

    - If yes, have you requested waivers of any of the ICF/MR regulations that have proven to be obstacles?
    - What were the outcomes of the requests for the waivers?

13. Has the need to upgrade the state institutions to meet XIX standards served to stimulate the development of small ICF/MRs in the community?

14. Will your state be able to comply with the federal ICF/MR standards by July, 1980?

    - If no, will you request an extension and for what reasons?

15. How are rates determined under the Title XIX, ICF/MR program?

    - For small facilities?
    - For large facilities?

- What method or reimbursement is used (e.g., retroactive, prospective payments)?

16. A number of federal officials believe that current reimbursement policies for state run ICF/MRs provide incentives to maintain large institutions. Do you think this is true?

    - If current federal rules were changed to reduce Title XIX reimbursement rates to large state facilities, what effect would this have on the state's progam? Would this policy stimulate the development of community residences?

    (*Note: Obtain any suggestions on how to accomplish the above.*)

17. Have the Independent Professional Reviews and Utilization Reviews of ICF/MR providers been helpful to you in monitoring their performance?

    - Have you encountered any problems with these review procedures?

    - If yes, please describe.

18. Have you developed any specialized management information systems applicable to ICF/MR programs?

    - If yes, please describe.

19. Have you encountered any particular problems with the certificate of need process as it applies to small, community ICF/MR providers?

    - If yes, please describe.

20. What proportion of beds (or if not available, proportion of funds) available to mentally retarded persons in the community is supported by: (please indicate a percentage)

    _____SSI
    _____Title XIX
    _____Title XX
    _____State funds
    _____County/local government
    _____Other, please specify_____

21. What proportion of beds in the state's institutions for the mentally retarded is funded by: (please indicate a percentage)

_____Title XIX
_____State funds
_____County/local government
Other, please specify_____

22. How would changes in other funding streams (e.g., SSI, federal housing, etc.) enhance the development of residential arrangements for developmentally disabled persons in your state?

- How would such changes reduce current or potential reliance on Title XIX for such purposes?

(*Note: If time allows, please ask the following two questions.*)

23. Under the current definition of developmental disability as defined in the ICF/MR regulations, how many additional ICF/MR beds would be needed to meet unmet demand? (Please give your best guess/estimate.)

24. As you know, there is a new definition of developmental disability which has been interpreted to include several new groups, including the chronically mentally ill. What will be the impact of this new definition on the ICF/MR program in your state?

(*Note: Ask for any additional contacts if certain data or information could not be supplied.Also, ask the interviewee to send any relevant materials.)*

Privately Administered MR Residential Facilities

Less Than 16 Beds

ICF/MR Facilities	PRESENT: As of June 30, 1979	PRESENT: July 1978 to June 1979	FUTURE: As of June 30, 1984	FUTURE: July 1983 to June 1984	Clarifying Comments
Total no. of facilities					
Total no. of licensed/certified beds					
Range of beds per facility					
Percent of clients referred from public MR institutions					
Percent mildly/moderately retarded					
Percent non-ambulatory					
Percent mobile non-ambulatory					
Total cost (operating)					
Federal share					
State share					
Local share					
Average per diem					
Per diem range					
Total conversion costs (July 1974 - June 1979)					
State share					
Local share					
Total conversion costs (July 1979 - June 1984)					
State share					
Local share					

State/County Administered MR Residential Facilities

Less Than 16 Beds

ICF/MR Facilities	PRESENT: As of June 30, 1979	PRESENT: July 1978 to June 1979	FUTURE: As of June 30, 1984	FUTURE: July 1983 to June 1984	Clarifying Comments
Total no. of facilities					
Total no. of licensed/certified beds					
Range of beds per facility					
Percent of clients referred from public MR institutions					
Percent mildly/moderately retarded					
Percent non-ambulatory					
Percent mobile non-ambulatory					
Total cost (operating)					
Federal share					
State share					
Local share					
Average per diem					
Per diem range					
Total conversion costs (July 1974 - June 1979)					
State share					
Local share					
Total conversion costs (July 1979 - June 1984)					
State share					
Local share					

State/County Administered MR Residential Facilities

(including state operated institutions)
16 Beds and Over

ICF/MR Facilities	PRESENT		FUTURE		
	As of June 30, 1978	July 1978 to June 1979	As of June 30, 1984	July 1983 to June 1984	Clarifying Comments
Total no. of facilities					
Total no. of licensed/certified beds					
Range of beds per facility					
Average no. or percent of beds occupied					
Percent of clients referred from public MR institutions					
Percent mildly/moderately retarded					
Percent non-ambulatory					
Percent mobile, non-ambulatory					
Total cost (operating)					
Federal share					
State share					
Local share					
Average per diem					
Per diem range					
Total conversion costs (July 1974- June 1979)					
State share					
Local share					
Total conversion costs (July 1979 - 1983)					
State share					
Local share					

Privately Administered MR Residential Facilities

(including privately operated institutions, nursing homes, intermediate care facilities, etc. either certified as ICF/MRs or serving primarily mentally retarded clients)

16 Beds and Over

ICF/MR Facilities	PRESENT: As of June 30, 1978	PRESENT: July 1978 to June 1979	FUTURE: As of June 30, 1984	FUTURE: July 1983 to June 1984	Clarifying Comments
Total no. of facilities					
Total no. of licensed/certified beds					
Range of beds per facility					
Average no. or percent of beds occupied					
Percent of clients referred from public MR institutions					
Percent mildly/moderately retarded					
Percent non-ambulatory					
Percent mobile, non-ambulatory					
Total cost (operating)					
Federal share					
State share					
Local share					
Average per diem					
Per diem range					
Total conversion costs (July 1974- June 1979)					
State share					
Local share					
Total conversion costs (July 1979 - 1983)					
State share					
Local share					

Glossary of Terms

Intermediate Care Facility for the Mentally Retarded (ICF/MR)

A facility serving mentally retarded persons and others with related conditions whose primary purpose is to provide health and rehabilitation services. Within such facilities, each resident for whom payment is sought must have an approved plan as stipulated in Title XIX regulations and must be receiving active treatment.

Public MR Institutions

A state or county administered comprehensive institution, residential school, hospital or state center providing services on a 24-hour, seven day per week basis to more than 16 individuals. Such facilities may or may not be ICF/MR certified.

State/County Administered ICF/MR Facility—Less Than 16 Beds

A state or county administered ICF/MR facility serving less than 16 individuals *off the grounds* of a public MR institution.

State/County Administered ICF/MR Facility—16 Beds and Over

That portion of a public MR institution that has been certified under Title XIX to receive reimbursement for ICF/MR services. This category should include the sum total of all such units even though any given unit may number less than 16 beds.

Non-Ambulatory Clients

Individuals whose physical impairments make it impossible for them to walk and/or move without assistance and who are incapable of survival without such assistance.

Mobile, Non-Ambulatory Clients

Individuals who are capable of walking and/or moving with the assistance of a mechanical device (e.g., wheelchair, walker, etc.) and who are capable of survival without assistance.

Total Cost (operating)

Total yearly operating budget(s) excluding capital improvements or repair costs amounting to more than $25,000.

Per Diem

Operating costs or charges per client day for residential arrangement.

Total Conversion Cost

Total amount of funds in the given time period required to bring residential facilities up to certification standards for Title XIX reimbursement for ICF/MRs. Costs are further broken down according to state and local (public) shares of such expenses.

Clarifying Comments

Any significant factors that could lead to the misinterpretation of the data. For instance, it may be noted that the average per diem for the state/county administered MR residential facilities in a given state does not include a depreciation factor, whereas such an allowance is included in the privately administered MR residential facility per diem figures.